



**HCFA ON-LINE: MARKET RESEARCH
FOR BENEFICIARIES
SECOND FOCUS GROUP REPORT**

Prepared for:

Health Care Financing Administration
Contract No. 500-95-0057/T.O. #2

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January 12, 1998

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Market Research on the Information Needs of HCFA Beneficiaries Focus Groups with Beneficiary Subpopulations and People About to Enroll in Medicare

EXECUTIVE SUMMARY

This report is one of a series of studies for the HCFA Market Research for Beneficiaries project. This project is designed to help HCFA better understand the information needs of its primary customers, Medicare beneficiaries, and to identify the best strategies for communicating information to them. The project uses three complementary data collection approaches—an inventory of existing communication strategies, focus groups with beneficiaries, and surveys of beneficiary populations—to provide information that is broad in scope, deep in content, and representative of the population.

This report summarizes the findings from focus groups with African-American, Hispanic, dually eligible, and rural Medicare beneficiaries, and with 64-year-old people about to enroll in Medicare. These focus groups were conducted in several locations around the country. Subsequent reports will present findings from focus groups held with other beneficiary subgroups. As with other reports from this project, the findings are organized around the two principal research questions: What information do beneficiaries want and need? and What is the best way to communicate information to them?

Although the report is organized around particular beneficiary characteristics (race, ethnicity, residence, Medicaid eligibility), these characteristics may not be the most important factors defining beneficiaries' information needs and preferences. Within most of the subgroups, participants varied considerably on other characteristics that may be equally or more highly associated with information needs, such as level of education, health status and family circumstances.

Beneficiaries' Information Needs

The general population focus group report identified three styles of beneficiary information-seeking behavior: proactive, reactive, and passive. Among the general population focus group participants, the reactive mode dominated—beneficiaries would seek information for a specific situation when it arose and preferred getting that information from a single source. The general beneficiary population focus groups probably also included a higher proportion of proactive information-seekers than the Medicare population as a whole because of the nature of focus group recruiting.

The subpopulation focus groups described in this report contained a higher proportion of apparently passive information-seekers than did the general population focus groups. It is likely that some of this difference is due to idiosyncratic differences in recruiting strategies. For example, it was necessary to rely on Medicare eligibility lists more strongly for some beneficiary subpopulations than for others that were easier to identify through standard market research recruiting channels. Nonetheless the higher proportion of passive participants in the groups reported here undoubtedly reflects a similar pattern in the population.

Some findings about information needs held-up across the beneficiary subpopulations included in this report. (People about to enroll have a somewhat different set of needs, and will be discussed separately.)

- More subgroup participants need basic information about the Medicare program than do participants in the general population groups.
- The subgroup participants were less likely to understand the functional distinctions between the government agency that runs Medicare, Medicare contractors, and supplemental insurers.
- Subgroup participants were more concerned than those in the general population about the future of Medicare. More vulnerable beneficiaries are generally more worried about funding cuts and their likely effects.
- Like participants in the general population, subgroup participants rely on family and friends for referrals to primary care physicians, and on primary care physicians for referrals to specialists.
- Also like general population participants, subgroup participants feel that they get enough information about staying healthy, although some find the information contradictory, and others find it difficult to understand.
- Subgroup participants are as likely to be suspicious of Medicare HMOs as general population participants. They cite concerns about quality of care and provider choice, although fewer subgroup participants seem to be well informed about Medicare HMOs.

The second Inventory Report noted that lower income beneficiaries' information needs are likely to span other social services as well as Medicare. In the focus groups, this point was particularly apparent for **dually eligible** beneficiaries, who often had difficulty distinguishing between Medicaid and Medicare. Some participants expressed a need for more information about Medicaid eligibility and spend-down, while others talked about cash benefits from SSA or SSI in the same context as Medicare.

Table 1 summarizes the information needs (as well as preferred sources) for the beneficiary subgroups studied and for people about to enroll. Among the focus group participants, **Spanish-speaking Hispanic** beneficiaries had the most basic information needs. At least half of the Spanish-speaking participants were illiterate (in Spanish as well as English) which compounds their difficulties getting

information. As noted in the second Inventory Report, many beneficiaries of Hispanic descent have no previous experience with health insurance, a further compounding factor. Despite their lack of basic information, Spanish-speaking beneficiaries shared many of the concerns about Medicare expressed by other participants, such as fraud and continued funding of the program.

African-American beneficiaries expressed some interest in gaining access to information about chronic conditions that are particularly prevalent among African-American beneficiaries. Findings from the second Inventory Report suggested that African-Americans have more difficulty understanding managed care than other beneficiaries. Although the focus groups did not expressly address this topic, spontaneous discussions about Medicare HMOs indicated that African-Americans had suspicions about them that were similar to those expressed in other groups.

Rural beneficiaries were most likely to be either proactive or passive information-seekers. Relatively few described themselves as reactive information-seekers. Rural residents also were more aware of whether physicians accepted assignment than other participants, because fewer providers accept assignment in rural areas, compared with urban and suburban areas.

People about to enroll in Medicare are obviously different from beneficiaries in that they have no personal experience from which to learn; the general population focus group report noted that most beneficiaries learn about Medicare through experience. Those 64-year-olds with spouses who are already beneficiaries and those who have dealt with Medicare for a parent are generally more informed about program basics than others. Those without any Medicare experience may not know how they enroll, what being on Medicare means for their existing health insurance and providers, and what their out-of-pocket responsibilities will be. Those who are aware that Medicare usually becomes the primary payer need information on supplementary insurance and Medicare managed care options. Different individuals among the 64-year-old focus group participants demonstrated or described each of the information-seeking strategies (proactive, reactive, and passive) identified in the first focus group report. The challenge for HCFA is how to make available a broad array of basic and more detailed information that will meet the needs of these different information-seeking styles, at the critical time just before enrollment.

Beneficiaries' Preferred Sources of Information

Medicare deals with personal and highly salient subjects—health and finances—and thus it is particularly important for information sources to be trusted and for information formats to be familiar. For individuals whose cultural background are different from the majority or whose education or life

experience with “mainstream” American society is relatively limited, these needs for trusted sources and familiar formats become even more important. These factors (different cultural background, low education, lack of exposure to mainstream society) are particularly prevalent among the beneficiary subgroups included in this report. (Again, people about to enroll are different from the beneficiary subgroups studied, and will be discussed separately.) Table 1 presents preferred sources of information identified in the focus groups for each subgroup studied. Some further highlights of the findings are presented in the following paragraphs.

The general population focus group report noted that most beneficiaries did not know HCFA by name. Once HCFA’s role was explained to them, general populations beneficiaries ranked the agency high on trust. The second Inventory Report suggested that ethnic minorities might have less trust in the government than the general population. Findings from the focus groups reported here do not confirm this suggestion. All but one of the subgroups ranked HCFA higher on trust than did the general population participants. Dually eligible beneficiaries ranked HCFA considerably lower on trust, perhaps reflecting their suspicion of government agencies in general and the continuing question of eligibility for Medicaid. Thus, the focus groups indicate that for at least some segments of the subgroup populations, HCFA may be a welcome source of information on Medicare.

Beneficiary subgroup participants were similar to general population participants in their opinions about family and friends as sources of information. These sources are viewed as valuable if they have experience as Medicare beneficiaries or are medical professionals. Friends and family without special experience or expertise are seen as insufficiently informed to serve as useful sources of information. Family and friends were important links to information for **Spanish-speaking Hispanic** participants, particularly when information is not available in Spanish. This reliance on family can be problematic for Spanish-speaking Hispanic beneficiaries if family members are only sporadically available or are not themselves fluent in English or in Spanish.

Medical providers are an important information source for many subgroup participants. Medical providers are the one universal, in-person contact with the system. Beneficiaries with less education or skill in using “the system” have almost no choice but to trust their medical providers.

AARP was a highly trusted and useful source of information about Medicare for the general population participants. The high rankings for AARP carried over into all of the subgroups except **Hispanic** beneficiaries (both Spanish- and English-speaking), many of whom never heard of AARP.

Community organizations received low ranks as information sources from general population participants. Many of the subgroup participants also had little contact with community

organizations regarding information about Medicare. Again, the **Spanish-speaking Hispanics** were an exception. Spanish-speaking Hispanic beneficiaries; particularly those in senior housing and those without helpful family members, relied on community sources for what often was their small amount of information about Medicare. Participants recruited for the focus groups reported here were generally more highly educated than the U.S. population over 65. Spanish-speaking Hispanic participants were the only exception. Thus, the individuals most likely to be reached by community organizations (less educated, more passive information seekers, perhaps with relatively few social contacts) may be under-represented because of our focus group recruiting processes.

In addition to the differences already mentioned, **Spanish-speaking Hispanic** participants were different from other subgroups and the general population in other ways regarding information sources. For example, they rarely used Medicare contractors as a source of information, and many were unfamiliar with this potential resource. When Spanish-speaking Hispanic beneficiaries need Medicare information, they tend to go in-person to the local office of the Social Security Administration (SSA), and they often go with a family member.

Dually eligible participants reported fewer clear preferences for information sources compared with the general population or any other subgroup. Some dually eligible participants indicated that as long as the system worked, they really didn't need any information. Others expressed general frustration with the system because they really didn't trust anyone. Reaching these beneficiaries will be a particular challenge for HCFA.

Rural participants were the only subgroup to mention privacy of information as a criterion for ranking information sources. The importance of privacy led to lower rankings for family and friends and higher rankings for "official" sources compared with rankings from the general population. Rural residents were better able than other participants to distinguish between supplemental insurers, of whom they are suspicious, and Medicare contractors, who they tend to trust.

People about to enroll in Medicare were quite different from beneficiaries in their preferences for information sources. They obviously had had no personal experience with Medicare contractors or supplemental insurers, except perhaps for exploring their options. People about to enroll in Medicare were no more familiar with HCFA than were beneficiaries, but they were very enthusiastic about getting information from HCFA. Also, many individuals about to enroll in Medicare counted on employers or former employers for information on their health insurance options as they approached Medicare eligibility. Somewhat surprisingly, the participants about to enroll in Medicare had very low opinions of medical providers as information sources.

Beneficiaries' Preferences for Information Media

Like those in the general population, subgroup participants prefer talking to people in-person or on the telephone, and they prefer to receive printed material over other media. Rural residents were the most likely to prefer the telephone, while Spanish-speaking Hispanic participants were most likely to seek information in person. Several groups stressed the need for printed materials that are easier to understand than the current Medicare Handbook. The second Inventory Report suggested that some subgroups need customized strategies for presenting information because of educational, cultural, and language differences. Spanish-speaking Hispanic beneficiaries need information in Spanish. Thus, they are one subgroup who would benefit from customized information presentation. The Spanish-speaking participants did not get much information from printed material, both because much of it is not in Spanish and because many of them do not read Spanish or English. Many were also hesitant to make telephone calls for information unless they knew for certain that a Spanish-speaking person would be available at the other end of the line. Our focus group results suggest that it may be more difficult to identify other groups of beneficiaries who would benefit from customized strategies because their needs and preferences depend not only on demographic factors used to define the groups we studied. Needs and preferences also depend on person-specific factors such as where they live, the types of social support networks they have, and their education levels, among other things.

General population participants had almost uniformly low opinions of the mass media as sources of information about Medicare. Similar attitudes were echoed in the subgroup discussions reported here. Some proactive information seekers found radio, television, newspapers, and magazines to be important sources of new information, even if they had to go elsewhere to get more details or to determine how accurate the information was. Their positive evaluations seemed related to their inclination and ability to synthesize and evaluate information from multiple sources. **Spanish-speaking Hispanic** participants and some **dually eligible** participants found radio and television to be important sources of information. This observation applies particularly to communities where the medium is in the language or idiom of the listener/watcher—for example, urban areas with large Spanish-speaking populations such as Los Angeles or Miami. In these communities, positive evaluations of mass media resources may be related to limited access to or understanding of other media.

Beneficiary subgroup participants were similar to those in the general population in their views on using computers and the Internet to get information about Medicare or health concerns. Some felt it would be interesting to try this medium, but most felt that it was a medium for the next generation. Subgroup participants were also similar to those in the general population in their attitudes towards automated telephone systems. Most found them frustrating. Finally, videotapes were used infrequently

by subgroup participants to get information about health care. Access to video players is particularly limited among lower income populations.

People about to enroll in Medicare were more positive about radio and television than any other beneficiary participants. They were also more positive about automated telephone systems, focusing expressions of frustration on poorly designed systems. The 64-year-old participants were no more likely than beneficiaries to view computers and the Internet as important potential information media; the “next generation” does not include them.

Table 1. Summary Information Needs and Trusted Sources for Beneficiary Subgroups and People About to Enroll

	African-Americans	Hispanic Americans (Spanish-speaking)	Dual Eligible Beneficiaries	Rural Residents
Information Needed	<ul style="list-style-type: none"> • Basic program information, such as the difference between Part A and Part B • Relationship between Medicare and supplementary insurance • Managed care options • Choosing a supplement • Practical information on chronic conditions disproportionately affecting black people 	<ul style="list-style-type: none"> • Basic program information, such as whether, how much, and when they need to pay for medical care • Basic insurance information 	<ul style="list-style-type: none"> • Difference between Medicare and Medicaid, how they work together • Medicaid eligibility rules • How spend-down works 	<ul style="list-style-type: none"> • Coverage of services • What providers accept assignment • Choosing supplementary plans
Trusted Sources of Information	<ul style="list-style-type: none"> • AARP/senior groups • HCFA 	<ul style="list-style-type: none"> • Medical providers • Family members • SSA • Local radio/TV • Community organizations 	<ul style="list-style-type: none"> • Medical providers • Medicaid offices • AARP 	<ul style="list-style-type: none"> • Medicare contractors • Medical providers • HCFA

Market Research on the Information Needs of HCFA Beneficiaries General Medicare Population Focus Groups

1. INTRODUCTION

The Health Care Financing Administration (HCFA) market research initiative was developed to improve HCFA's service to its customers and partners and to promote effective communication strategies while incorporating innovative technologies and systems. The four components of the overall market research initiative include: (1) identifying the information needs of HCFA customers through market research; (2) improving the usefulness of HCFA data and information; (3) enhancing communication capabilities; and (4) developing formal evaluation and feedback mechanisms to ensure continuous improvement of HCFA activities. The focus group research reported here is part of the HCFA market research effort to identify the information needs of Medicare beneficiaries.

1.1 Overview of the Market Research Project on the Information Needs of HCFA Beneficiaries

The Market Research for Beneficiaries initiative is dedicated to helping HCFA understand the flow of information between HCFA and Medicare beneficiaries. The market research activities focus on two questions:

- What information do beneficiaries want and need from HCFA?
- How can that information be most effectively made available?

Our goal is to implement data collection and analysis activities that will help HCFA understand beneficiaries' information needs and identify effective communication strategies. We are conducting three data collection activities: an inventory of information needs and effective communication and dissemination strategies, focus groups with Medicare beneficiaries, and surveys of the Medicare population. While complementary, each of the three data gathering approaches has particular strengths that will contribute to a more thorough overall understanding of the research questions. For example, the inventory research ensures that information about strategies for identifying and addressing beneficiaries' needs and preferences builds on the cumulative experience of diverse organizations involved in distributing information about health care, health care services and health care options. The focus group research is collecting detailed qualitative information from current Medicare beneficiaries and from individuals about to enroll in the Medicare program. The Medicare beneficiary

survey activities provide a mechanism for producing population estimates reflecting individuals' attitudes toward and needs for information.

In order for HCFA to respond to the varying needs of a diverse Medicare population, the Market Research for Beneficiaries project is being conducted in three phases that are illustrated in Exhibit 1-1. The focus of the first phase was the general Medicare population. It included an inventory of communication strategies effective with Medicare beneficiaries in general (see the First Inventory Report) and focus groups with individuals drawn from the general population of Medicare beneficiaries (see the First Focus Group Report). The Phase 1 research activities will also include analyses of results from survey research conducted with the general Medicare population. As illustrated in Exhibit 1-1, subsequent phases of the project will provide similar types of information for selected groups of Medicare beneficiaries. Phase 2 research activities cover five beneficiary subpopulations: African-American beneficiaries, Hispanic beneficiaries, beneficiaries who are dually eligible for Medicare and Medicaid, rural beneficiaries, and those about to enroll in Medicare. Phase 3 research activities will cover four beneficiary subpopulations: beneficiaries with low educational attainment, beneficiaries who are hard of hearing, beneficiaries with vision limitations, and one additional subpopulation to be identified by project staff at HCFA. Within each research phase, the Market Research for Beneficiaries initiative will produce separate inventory, focus group and survey reports for the selected Medicare subpopulations. The project's Synthesis Report will integrate results across the three sets of research activities and across the three phases, focusing on implications for HCFA communication strategies.

Exhibit 1-1

Research Activities and Study Populations for Three Phases of Market Research

Research Phase	Research Activities	Study Populations
Phase 1	Inventory Focus Groups Survey Data Analysis	General Medicare Beneficiaries
Phase 2	Inventory Focus Groups Survey Data Collection and Analysis	African-American Beneficiaries Hispanic Beneficiaries Dually-Eligible Beneficiaries Rural Beneficiaries Individuals About to Enroll in Medicare
Phase 3	Inventory Focus Groups Survey Data Collection and Analysis	Beneficiaries with Low Educational Attainment Beneficiaries with Hearing Limitations Beneficiaries with Vision Limitations Another Subpopulation to be Identified

The current report focuses on five beneficiary groups: African-American beneficiaries, Hispanic beneficiaries, beneficiaries who are dually eligible for Medicare and Medicaid, rural beneficiaries, and those about to enroll in Medicare. The focus group research reported here builds upon our initial inventory and focus group research with beneficiaries from the general Medicare population. The focus group research reported here also draws on results from the Second Inventory Report which reported on communication strategies for the Phase 2 beneficiary populations. The goal of our Phase 2 focus group research was to collect information directly from beneficiaries within each of the selected Phase 2 beneficiary populations to:

- Explore beneficiaries' perceptions of the information available to them;
- Identify information gaps that beneficiaries are aware of;
- Investigate additional information gaps that beneficiaries become aware of through discussions of their experiences;
- Identify sources of information that are particularly accessible to beneficiaries;
- Identify sources of information that are trusted by beneficiaries;
- Investigate beneficiary reactions to media and methods for communicating information about health and health care.

It is important to note that our aim with the Phase 2 focus groups is to understand information experiences, needs and preferences within each of the selected beneficiary subpopulations. Consequently, our data collection and analytic efforts focus on identifying important results within each of the selected subpopulations. This report is structured to present results separately for each group of beneficiaries. The next section of this report gives a more detailed overview of the organizational structure for this focus group report.

1.2 Overview of Focus Group Report

Chapter 1 of this focus group report gives an overview of the HCFA Market Research project on the information needs of HCFA beneficiaries. Chapter 2 gives general information about focus group methods and specific information about the Phase 2 focus group design. It includes descriptions of the focus group discussion guide, the focus group participants and our focus group analyses. Chapters 3 through 5 present our major findings. Chapter 3 focuses on results relating to beneficiaries' information needs. Chapter 4 focuses on results relating to beneficiaries' attitudes toward alternative sources of information. Chapter 5 focuses on results relating to beneficiaries' reactions to and impressions of alternative information channels or media. We use quotations from focus group participants extensively in Chapters 3 through 5 to illustrate our main findings. The quotations are presented in text boxes to

make them easy to identify. In addition, we use text box titles to highlight findings that the quotations were selected to illustrate.

Chapters 3 through 5 begin with summaries of major results from focus groups conducted with individuals drawn from the general population of Medicare beneficiaries. Then, each chapter presents focus group results separately for each of the five selected groups of HCFA beneficiaries. This structure reflects our major goal: to identify information experiences, needs and preferences, separately for each of the five selected groups of beneficiaries. In Chapters 3 through 5, we use italic font to emphasize preliminary implications suggested by focus group results.

The results presented here are only one resource for the HCFA Market Research for Beneficiaries initiative. As illustrated in Exhibit 1-1, we will be conducting additional focus groups with other beneficiaries. Also, our market research design includes literature review activities, intensive interviews with experts who have considerable experience developing and delivering information for Medicare beneficiaries, and surveys of the Medicare population. Given the complimentary strengths of these data collection methods, it is important to note that implications identified here will be amplified, modified or revised based on results from the other market research components and phases. Chapter 6 synthesizes major results about information needs, preferred information media, preferred information sources and preliminary recommendations for each Phase 2 study subpopulation. An important goal of the project's Synthesis Report will be to identify a fully informed set of recommendations developed by considering results from different research activities across the range of study populations.

2. FOCUS GROUP METHODS AND DESIGN

2.1 Overview of Focus Group Methods

Focus group methods used in market research fall within the domain of qualitative research methods. The aim of focus group research is to explore participants' experiences, attitudes and motivations. Focus group research is descriptive and inductive. The goals of focus group research differ from and are complementary with the goals of program evaluation research and survey research which are designed to estimate and evaluate quantifiable phenomena (e.g., Taylor and Brogden, 1984; Patton, 1990). The aim of focus group research is to **understand** attitudes and experiences while the aims of survey and program evaluation research are to **quantify and estimate** attitudes and experiences.

With the qualitative focus on understanding individuals' experiences and perspectives, focus group methods typically involve small numbers of participants selected according to study-specific criteria. In addition, research protocols and discussion guides are open-ended to ensure that participants report their experiences using their own words. These characteristics highlight the strengths and limitations of focus group research. Focus group methods are particularly appropriate for collecting data on individuals' experiences with Medicare in terms that reflect their own perspectives and for generating hypotheses about the experiences of individuals in different situations or from different backgrounds. Focus group methods are generally not suitable for research that requires evaluating the prevalence of particular experiences within or across populations or drawing inferential conclusions about group differences.

2.2 Focus Group Locations

The focus groups reported here were conducted in 10 locations: Bethesda (Maryland), Hagerstown (Maryland), Miami, Chicago, Houston, Pasadena (California), Hartford (Connecticut), Roanoke (Virginia), Baltimore, and San Antonio. These locations were selected to reflect a range of health care markets, based on documentation in the First Inventory Report that consumers' experiences and information needs are likely to differ depending on market factors. Exhibit 2-1 identifies the focus groups conducted in each location. For groups selected to be homogeneous with respect to race or ethnicity, we hired focus group moderators who were members of the same racial or ethnic groups. All of the Hispanic focus groups were led by bilingual moderators.

Exhibit 2-1
Focus Groups Conducted in Each Location

Location	Beneficiary Subgroups
Bethesda, Maryland	64 year olds (1 focus group)
Hagerstown, Maryland	Rural (1 focus group)
Miami, Florida	64 year olds (1 focus group) Spanish-speaking Hispanic (1 focus group of males and females)
Chicago, Illinois	African-American (1 focus group) Rural (1 focus group)
Houston, Texas	Rural (1 focus group) Spanish-speaking Hispanic females (1 focus group)
Pasadena, California	African-American (1 focus group) Dually eligible (1 focus group) Spanish-speaking Hispanic females (1 focus group) Spanish-speaking Hispanic males (1 focus group)
Hartford, Connecticut	64 year olds (1 focus group) Spanish-speaking Hispanic females (1 focus group) Spanish-speaking Hispanic males (1 focus group) Dually eligible (1 focus group)
Roanoke, Virginia	Rural (1 focus group)
Baltimore, Maryland	African-American (2 focus groups) Dually eligible (1 focus group)
San Antonio, Texas	64 year olds (1 focus group) Dually eligible (1 focus group) English-speaking Hispanic females (1 focus group) English-speaking Hispanic males (1 focus group)

2.3 Focus Group Discussion Guide

When effectively moderated, focus group interactions simulate conversations that might naturally occur around a given topic. The give-and-take among group members elicits ideas and reactions that might not be revealed in individual interviews. The focus group discussion guide is an important tool in helping moderators lead groups effectively. A good discussion guide helps moderators to encourage spontaneous participation, to react to group dynamics, to ensure participation from all group members, and to guide group discussion away from topics that are irrelevant to research goals while leaving room for the discussion to address unanticipated topics that are relevant to overall research goals.

We worked closely with HCFA project staff to develop initial discussion guides and to revise the discussion guide iteratively based on issues that emerged from ongoing inventory research and from early focus group discussions. We developed one discussion protocol that was sufficiently general to serve as the moderator's guide for all focus groups with current beneficiaries. We used the current beneficiary discussion guide to develop the discussion guide for focus groups with individuals who were about to enroll in Medicare. The two discussion guides covered the same set of general topics, but the specific discussion questions differed somewhat for focus groups with current beneficiaries and for focus groups with individuals about to enroll in Medicare. For example, all groups were asked to describe recent attempts to get information from or about the Medicare program. Moderators asked current beneficiaries to describe any attempts to get information. Moderators asked individuals about to enroll in Medicare separate sets of questions to distinguish between attempts to get information for themselves and for others already enrolled in Medicare.

The focus group agenda and discussion guide topics were designed so that the groups would spend roughly half of each two-hour discussion talking about the **kinds** of information beneficiaries want and need from HCFA and the other half of the discussion talking about **effective methods** for making information available to beneficiaries. It is clear from the focus group results in Chapters 3 through 5 that the guide was sufficiently open-ended to elicit subgroup specific information needs and concerns. Exhibit 2-2 gives an overview of the topics included in the discussion guides, and the moderator guides are included as Appendix A.

Two sections of the discussion guides were modified roughly half-way through the focus group data collection based on early results and emerging issues. In the sections focusing on information about supplemental insurance, we added questions about information on Medicare HMOs. The new discussion questions asked about the kinds of information participants received from Medicare HMOs and the kinds of information they would like to receive from Medicare HMOs. The revised discussion guides also included new questions about automated response units (ARUs) in the sections about toll-free telephone assistance and automated phone menus. these questions asked participants about their reactions to using automated menus under several hypothetical scenarios. The discussion questions added to the discussion guides are identified as new questions in the guides in Appendix A.

Exhibit 2-2
Overview of Focus Group Discussion Topics

Focus Group Topics
<p>Basic knowledge of Medicare program</p> <p>Familiarity with HCFA</p> <p>Recent Medicare information needs</p> <p>Recent attempts to get Medicare information</p> <p>Most important sources of Medicare information</p> <p>Most trusted sources of Medicare information</p> <p>Familiarity with and reactions to Medicare Handbook</p> <p>Gaps in Medicare information</p> <p>Information needs and preferred form:</p> <ul style="list-style-type: none"> • Supplemental insurance • Medicare HMOs • Primary care providers • Specialty care providers • Staying healthy and preventative care <p>Reactions to information media, including radio and television, newspapers and magazines, mail-out materials, videotapes</p> <p>Reactions to telephone resources, including automated response units (ARUs)</p> <p>Reactions to computerized resources, including the Internet</p>

2.4 Focus Group Participants

HCFA provided lists of Medicare beneficiaries and pre-enrollees in the selected locations, and focus group participants were recruited by market research firms in each area. The market research firms used the Medicare lists, their own lists of research participants, and other means of recruitment such as distributing flyers in senior centers and churches to identify eligible and interested participants. Early inventory results revealed that Medicare experiences and beneficiary information needs vary considerably depending on whether beneficiaries are enrolled in fee-for-service or managed care health plans. HCFA project staff decided early on that it would be counter-productive to recruit groups that mixed beneficiaries from fee-for-service and Medicare managed care plans. We conducted four focus groups for most of the selected subgroups of HCFA beneficiaries.¹ HCFA was concerned that the exploratory power of the focus group design would be diluted if half of the groups examined the experiences of beneficiaries

¹ We conducted eight focus groups with Hispanic beneficiaries.

under fee-for-service plans and half of the groups examined very different experiences of beneficiaries under Medicare managed care. HCFA has already completed several studies using qualitative research methods to explore beneficiaries' experiences with Medicare managed care (HCFA, 1995). Based on these considerations, HCFA determined that the groups included here should consist only of beneficiaries enrolled in fee-for-service plans.

We developed recruiting procedures to identify Medicare beneficiaries who were 65 years old or older and who belonged to the selected beneficiary subpopulations. We also developed recruiting procedures to identify individuals who were 64 years old and not yet enrolled in the Medicare program. Our focus group screening questionnaire is included as Appendix B. For most selected subpopulations, recruiters were instructed to fill focus groups with men and women and a mix of ages. Some groups were recruited to be homogeneous with respect to race or ethnic background, but all other groups were recruited to reflect a mix of race or ethnic backgrounds. Preliminary results from one mixed gender focus group with Hispanic beneficiaries revealed difficulty eliciting detailed information from Hispanic females. Subsequently, we recruited separate focus groups of Hispanic males and Hispanic females, which ensured detailed data collection from both genders.

Exhibit 2-3 gives detailed demographic information about focus group participants for each study subpopulation.

2.5 Focus Group Data Analysis

The basic questions this research seeks to answer are:

- What information do Medicare beneficiaries want and need?
- How would they like to get it?

The focus group discussion guides were structured to collect extensive information on both general topics, and the discussion data permit in-depth review and analysis. All focus group discussions were recorded on videotape and on audiotape. Discussion transcripts were made from the audiotaped discussions. The Spanish-language discussions were translated and transcribed in English.² These transcripts were our primary analytic resource. In addition, note-takers were present at most groups to take detailed notes on discussion content and flow. Note-takers documented important features of the composition and dynamics in each group and drafted summaries for most groups that identified important

² Spanish-language groups were also simultaneously translated into English so that English-speaking note-takers and observers could follow the discussion.

group characteristics and findings. The summaries and the video and audiotapes were secondary analytic resources. We used these materials to clarify and sharpen our analytic conclusions.

We conducted all focus group analyses separately by selected beneficiary subpopulation. This report focuses on five select subpopulations: African American beneficiaries; Hispanic beneficiaries; dually eligible beneficiaries; rural beneficiaries; and 64 year olds about to enroll in the Medicare program. Based on initial reviews of group transcripts and summaries for each subpopulation, we identified major themes and topics for each subpopulation and sorted electronic versions of the transcripts by topic so that we could review what beneficiaries from the selected subpopulations had to say about each general theme or topic. All quotations in the sorted transcript files were identified by group location and population, so it was possible to compare experiences and perceptions across locations. Some qualitative comparisons across subpopulations are also possible, but this report will focus on themes that emerged from the analyses performed separately for each selected subpopulation. The themes address the two general research questions, around which this report is organized.

Chapters 3 through 5 present the results from our focus group analyses. Chapter 3 focuses on identified beneficiary information needs, Chapter 4 addresses beneficiary perceptions of alternative information sources, and Chapter 5 details beneficiary reactions to and preferences across alternative information media. In these chapters, we have presented results separately for each subgroup to make it easy for readers interested in particular subpopulations to find relevant results. We start each chapter with a brief summary of major findings from the first focus group report, which contains results for focus groups conducted with individuals drawn from the general population of Medicare beneficiaries. We hope that these summaries will encourage initial comparisons across subpopulations. Chapter 6 synthesizes results from Chapters 3 through 5 for each study subpopulation. The later Synthesis Report will make comprehensive comparisons across the research methods and the subpopulations selected for study in this market research initiative.

Exhibit 2-3

Demographic Characteristics of Focus Group Participants by Beneficiary Subgroup

		U.S. Pop. Over 65	General Population	African American	Hispanic (Spanish)	Hispanic (English)	Rural
Number of Groups			12	4	6	2	4
Gender	Male	40.8	51.0	20.0	47.3	50.0	48.6
	Female	59.2	49.0	80.0	52.7	50.0	51.4
Age Group	Under 65	N/A	0.9	0	14.5	0	0
	65-69	29.6	50.0	51.4	36.4	44.4	25.7
	70-74	26.3	25.5	28.6	27.3	33.3	31.4
	75 and older	44.1	23.6	20.0	21.8	22.3	42.8
Race/Ethnicity	White, not Hispanic	86.2	84.7	0	0	0	91.4
	Black	7.2	13.3	100.0	0	0	8.6
	Hispanic	4.5	1.0	0	100.0	100.0	0
	Other	2.0	1.0	0	0	0	0
Education	Less than high school	31.1	7.6	25.7	82.7	11.1	20.0
	High school graduate	36.4	31.4	25.7	15.4	22.2	22.9
	Some college	18.3	32.4	25.7	1.9	44.4	37.1
	College graduate	9.0	20.0	14.3	0	11.1	11.4
	Advanced degree	5.2	9.5	8.6	0	11.1	8.6
Previous Focus	Yes	N/A	61.9	23.5	N/A	55.6	31.4
Group Experience	No	N/A	38.1	76.5	N/A	44.4	68.6

3. INFORMATION NEEDS OF MEDICARE BENEFICIARIES

The focus group protocol dealt with the information needs of beneficiaries in several areas: information about the Medicare program, information about supplemental insurance, information about choosing a health care provider, and information about staying healthy. In early groups, we attempted to exclude information about Medicare HMOs from the protocol because considerable qualitative research has been done on beneficiaries' needs for information about choosing an HMO and using managed care effectively (e.g., HCFA, 1995). Nevertheless, focus group participants often wanted to talk about managed care, and their comments revealed experiences and information needs that seemed important to this market research initiative. Therefore, we revised the focus group protocol roughly half-way through the research project to include specific questions about the types of information participants have received from Medicare HMOs and the types of information they would like to receive about Medicare HMOs. The revised guide was used with focus groups conducted in Baltimore and San Antonio.³ This chapter includes a section on "information about managed care" which covers results from early groups that were conducted before the guide was revised, as well as results from later groups where Medicare HMOs was explicitly included as a discussion topic.

3.1 Major Findings for General Population Beneficiaries

Broadly speaking, focus group participants from the general population of Medicare beneficiaries need two kinds of information: **general** information about the Medicare program and its structure and **situation-specific** information about how beneficiaries with specific needs can use the program to access care. The types of information beneficiaries prefer depends on health status, the presence of precipitating health events, and whether beneficiaries are proactive, reactive or passive information-seekers. Proactive information-seekers look for information from a variety of sources on a continual basis. They value accurate, up-to-date information, and generally make their own judgments about what's useful and what isn't. Reactive information-seekers look for answers to questions or problems as they arise, they prefer to access only information that is relevant to their immediate situation, and they usually don't want to have to pursue more than one source. Passive information-seekers seem to lack specific strategies for gathering information they need. They rely on information that is delivered to them automatically and on information from trusted advocates or resources.

³ The revised moderator's guide was used in other locations, and those results will be reported in later focus group reports.

Basic Program Information

Most participants in the general population focus groups were familiar with the Medicare program's basic features. They were confused about more detailed aspects of the program. Conversations revealed a reasonably high comfort level with the relationship between primary and secondary payers, and the distinctions between Medicare Parts A and B. However, in addition to often incorrectly identifying Medicare as a program run by the Social Security Administration, participants frequently had trouble differentiating among the Medicare program, the agency that administers Medicare, carrier insurers that pay claims for Medicare, and supplemental insurers.

Confusion about Who Administers Medicare

Participant: "I get from Social Security [information] about the Medicare... If there's anything they want us to know, my experience is it comes through them."

Moderator: "Okay, that's Social Security, but we're talking about Medicare, the health insurance part."

Participant: "But it amounts to the same thing, is what I was going to say."

Respondents reported that recent experiences trying to find information about the Medicare program were generally motivated by problems obtaining and/or paying for care. Participants gave mixed accounts of the outcomes of these experiences. Some were satisfied with the answers provided by such sources as the Explanation of Medicare Benefits form (EOMB), the Medicare Handbook, or their doctors. Others were unable to describe their coverage and did not recognize that there were existing resources to answer their questions about Medicare conventions and procedures. A large number of participants were uncertain about where to find information on benefits and coverage, and some of these beneficiaries were able to resolve their problems only through serendipitous contacts with resources who were willing to advocate for them.

Beneficiaries Rely on a Variety of Resources

"The rules state that... they are supposed to pay it so long as that letter is accompanied with that claim... they claimed in our case that they never received a letter... I volunteer at the hospital so I know some of the people there. And I went down to one of the girls who handles it and I explained the situation. She said, 'Leave it with me and I will take care of it.' Now how she did it I don't know but she did get it taken care of in her own way."

"I had bypass surgery and I handled all my paperwork... Well, I think that at last count my bills were two inches thick... But if it weren't for the Medicare Explanation of Benefits, which I think are wonderful, I could not nail down the providers when they make errors... I Xeroxed Medicare Explanation of Benefits and say, 'Haven't you looked at this?'... I want to applaud them."

Participants reported difficulty interpreting the terminology they encounter on Medicare billing and information materials. Although some participants were aware that HCFA provides definitions of terms on such forms as the EOMB, others suggested adding a glossary to the Medicare Handbook. Participants reported that they often learn to navigate the Medicare system by trial and error, which means that they experience frustration in sifting through contradictory information. In some cases, participants reported receiving correct information about coverage only after services were provided.

Learning about Medicare Through Experience and Trial-and-Error

“The information sheets that are prepared by computer are absolutely obscure... They use terminology that there’s no dictionary for. There’s no glossary provided. And the syntax they use is archaic.”

“Well, I’m fairly new. I just started in February. I have found that I don’t really know what’s going on... Some of the doctors don’t charge me anything... Some of the doctors make me pay... It’s very confusing to me.”

“What I finally figured out is, most of the doctors send it to Medicare. Medicare sends it to [my supplementary insurance] and then whatever didn’t get paid, the doctor bills for.”

“My wife needed therapy and... I listened to the doctor which is probably mistake number one. He says, ‘Don’t worry, you are covered by Medicare’... We went to the hospital for the therapy that she needed and when it came time to pay, the hospital sent me a bill that was larger than what Medicare paid... They said that Medicare pays 20 percent of what the hospital bills... In other words, the hospital billed \$1,000, Medicare approved \$500, they paid 80 percent of the \$500. I was billed 20 percent of the full \$1,000.”

“But the problem, again, is lack of information in terms of accessibility to the patient. The provider and the payer may know what they’re talking about, but the patient, in most cases, hasn’t the foggiest notion of what the arrangements are... I think we have to have full disclosure. We need to know what’s going on.”

Choosing a Provider

A few participants reported that they use medical associations and reference books to choose their medical providers. The rest were more likely to rely on recommendations from other trusted providers, friends and family, or on their own personal experiences. Participants generally agreed that training, certification status, and record of malpractice suits are important factors to consider when looking for qualified providers. Participants were also interested in assessing the communication skills or “bedside manner” of a potential primary care provider. Participants reported relying on advice from friends and family and their own experiences to gather information about interpersonal skills. Participants were not interested in accessing this kind of information through published provider lists or

referral services. Participants generally agreed that they rely on their primary care providers for referrals to specialists.

Selecting a Provider: Criteria and Resources

“If someone gave me a list of doctors... some information on a list of doctors, I still wouldn’t know which one to pick until I got right down to the nitty gritty and talked to him.”

“You go to your friends who have been dealing with a doctor for quite a few years. Find out... what kind of a doctor is he... If [they are] good friends, then you trust [them].”

“I’m getting on in years. The thing that perhaps is most important is to find someone who understands geriatrics, because you go to some younger doctor... and he’s dealing with ordinary run-of-the-mill type stuff and here you’re an old coot... [the doctor] doesn’t necessarily know.”

I think that... if you trust your primary care doctor, he is the one that’s going to refer you to the specialist.”

“And when you... [go] from one doctor to the next you get the same mentality, the same type of background and education that the other one had... without getting say an update or a younger person with a more liberal type of approach to an illness.”

Medicare HMOs

Participants expressed mixed feelings about Medicare HMOs. They liked the idea of lower costs and more extensive coverage, but were discouraged by restrictions on provider choice and perceived restrictions on access. Participants noted that their own providers’ participation in Medicare managed care would influence their decisions to join an HMO. Participants generally agreed that HCFA could play an important role in explaining how Medicare managed care works and the available options. Participants suggested creating a single source summarizing and comparing the benefits and costs of Medicare alternatives, including both managed care and fee-for-service plans. Participants felt that this kind of resource this would go a long way towards relieving the confusion many of them feel as they sort through the large quantities of materials mailed to them by managed care companies.

HCFA Could Provide Useful Information about Medicare Options

Moderator: “What kind of information would you like the [Medicare] program to provide?”

Participant: “How... Medicare would be compatible with the... HMO’s... payment and service.”

Participant: “Chart... at least the HMO companies. A comparison of coverage... straight down where you could look at it and read. A lot of times you would have to go through three or four or five articles... You forget what you have really looked at.”

Supplemental Insurance

For the most part, general population participants' responses to questions about their experiences choosing supplemental insurance divided them into three groups: those who understand Medigap options and how to get information about supplemental insurance; those who are less informed but have trusted sources to whom they have turned for help; and those who are thoroughly confused. It is important to address these varying degrees of knowledge by making information available in a variety of formats and from a broad range of sources. Participants mentioned some specific issues that they would like additional information on, including: insurance rates across companies; information about any restrictions on provider choice; and requirements and/or options for getting a second opinion.

Diverse Experiences Selecting Supplemental Insurance

"I had at least three companies that I was deciding from. I had all the information that I needed. They all send you charts. They tell you precisely what it is. The cost for Plan A through Plan F, I believe it is, or Plan G. These are all Medigap programs... So because the government has said you can only have A through F or G plans to offer, and they're all exactly the same, the only difference is the price. Therefore, the choice is comparatively easy."

"A friend of mine whom I trust. He researched my company pretty well and then I checked with my agent and he said it was a very good company and I bought it."

"I don't know if I had a choice. I don't know how I got [my supplemental insurance]. I really don't know."

Staying Healthy

Most participants agreed that they get plenty of information about staying healthy. Some mentioned that they appreciate receiving reminders about preventive care, such as the flu shot notices that periodically accompany Social Security checks. Participants reported having difficulty sorting through competing claims about healthy habits, and they believed that HCFA could address this information gap. Several respondents were confused by conflicting information about how to stay healthy, while others had trouble reconciling research results with their own experiences.

Potential Role for HCFA Reconciling Conflicting Information

"There's a lot of information. I wish there was some governmental agency that would discern which is good and have some [statistics]... on how it comes about."

Other Information Needs

In general, it was difficult for participants to respond when asked what information they need but do not currently have access to. Nonetheless, the focus group discussions elicited some suggestions. Beneficiaries asked for more specific information to help them track their claims; regular updates on policy and procedure changes in the Medicare program; a list of resources they can turn to for help with commonly asked questions or problems; stricter and more readily available guidelines to follow when they suspect fraud; clear communication about how Medicare is funded, and reassurance about the program's future.

Medicare Questions HCFA Could Answer

"It would be good if we had some sort of list that remains static, that doesn't change, with certain things if you want to call... Where to contact this person, that person, or this agency, that agency. And that doesn't change... [That would] be helpful in connection with trying to locate information."

Participant 1: "I think it would be a good, an extremely good, idea for... the government to keep us posted, maybe not by the month, but yearly, on the different benefits we can take advantage of or look for with our Medicare coverage."

Participant 2: "I think that would be wonderful... How do you know what the changes are, unless they point it out to you? And I just give up."

"My question is where does the money come from for Medicare? I know it's tax money. Is it Social Security? When people pay into Social Security over their working years, isn't that where the money is supposed to come from? It was supposed to be a large amount of money. Then I understood about the end of the 40's they began dipping into the fund for other purposes... That's my only question: Where is the money?"

3.2 Major Findings for African-American Beneficiaries

Focus group discussions with African-American beneficiaries suggest that the information needs of this subpopulation are similar to those of the general population. Participants from both segments need clearer information about such things as Medicare's current and future financial status, how the program works in conjunction with supplementary insurance, what services are covered for how long, and the advantages and disadvantages of Medicare HMOs. Beneficiaries from both groups rely on the recommendations of friends and family to choose their primary care providers, and they receive plenty of information on how to stay healthy. One noteworthy difference between general population and African-American beneficiaries' information needs was revealed in the section on staying healthy: African-American participants said they want more information about health care concerns that are specific to their race.

Basic Program Information

Most participants associated Medicare with the Social Security Administration. Across four focus group with African-American beneficiaries, no one mentioned HCFA or recognized the name when it was brought up by the moderator. This may be in large part because beneficiaries often turn to the Social Security Administration with questions about the Medicare program. Quite a few focus group participants reported that the Social Security Administration had filled their Medicare-related information needs.

Perceived Link Between Medicare and the Social Security Administration
Moderator: "What do you think of when I say Medicare?" Participant: "I think of Social Security. They're always sending me a lot of mail..." Moderator: "Do you remember the last time you tried to get information on the Medicare program?" Participant: "Just the question I'm asking now, but I talked to my girlfriend last week. And I just said, 'I'm going down to Social Security to find out something about it.'"

With HCFA's shift in focus to customer service and satisfaction, it will be important to help consumers recognize the services that HCFA provides. Accurate assessments of customer service will require that consumers make appropriate and correct attributions about provided services and information.

As with the general population, there was confusion among African-American beneficiaries over some features of the Medicare program. However, differences emerged on which aspects needed clarification. While general population participants seemed familiar with the relationship between primary and secondary payers, as well as Medicare Parts A and B, many of the African-American participants were not. Every group raised questions about whether or why one would need Part B, how much coverage is adequate, and how services get paid for. There were also questions about the types of services that are covered by Medicare, the extent of coverage, the wisdom of joining an HMO, and the relationship between earnings and health insurance coverage. *African-American beneficiaries are particularly likely to benefit from basic information that describes how the Medicare program is structured and how program components work together to provide health care coverage. This descriptive information should be provided in a variety of formats and media to increase the likelihood that it reaches the individuals who need it most.*

Confusion about Basic Medicare Components—Part A and Part B

“I’m here because I’d like to find out why I need Part A and Part B of Medicare.”

Participant 1: “I have a question. I want to know what check are you all sending every month and where does it go?”

Participant 2: “It’s the Part B. See, if you work, then your employer takes money out of your work check and Social Security coverage. And then when you get old enough to retire, you receive a check from Social Security.”

Participant 1: “Well, I guess I pay, but it’s deducted from my Social Security.”

Confusion About the Role of Supplementary Insurance

Participant 1: “I got to ask a question about... the insurance companies that pay claims to Medicare, who are they?”

Participant 2: “You mean the supplementary?”

“What’s happening is, my problem is I’ve got Medicare and I asked them last month if I had A and B and they said I had both of them and then I need Med Assistance. And see, if you have Medicare and Med Assistance, if you’ve got this other insurance, AARP, what’s happening is they said I’m wasting money paying AARP because if I have Med Assistance and Medicare, AARP is going to give that money to Med Assistance.”

Participant: “I would like to know how much Blue Cross and Blue Shield, how much do Medicare pay of that?”

Participant: “Okay. I’m like her. I am on Medicare, but I also have a supplemental Blue Cross and Blue Shield. And I just wanted to know... just what does Medicare pay?”

Participant: “Blue Cross and Blue Shield is supplementary. They’re paying what Medicare don’t pay. That isn’t the same thing. I don’t even know who pays.”

Participant: “Well, they show what Medicare has paid and what they’re paying.”

Participant: “Right. That’s what we’re trying to say, who pays Medicare?”

Moderator: “There is some confusion about who pays what.”

Participant: “So we need information.”

Participant: “Yes, who really pays Medicare, right.”

Confusion Between Medicare and Medicaid

“I have a girlfriend in Texas. And she was asking me, ‘How did you get on Medicare?’ And I got to thinking, I’m not on Medicare. I’m MediCal. Is there a difference? Maybe I’m on Medicare and don’t know it...”

Basic Questions About Medicare Coverage and Eligibility

Moderator: “What kind of information have you called to get from Medicare, in reference to Medicare?”

Participant: “I’ve called when they have disqualified a doctor’s charge. I’ve called about that, asked them why not. Some things are covered under certain circumstances. Other things are not.”

“Well, I want to know if this long hospital stay, you know, when do Medicare stop?”

Moderator: “Information about your Medicare program or any information at all that you were trying to get about the Medicare program.”

Participant: “Coverage, whether or not they provide coverage for a pre-existing condition.”

Participant: “Well, that would bring up a question in my mind and that is what kind of earnings or income, you know, would precipitate... is there an earnings level or is there an income level or something that means you would be more qualified or more eligible?”

Many participants reported frustration over recent experiences trying to obtain information about the Medicare program. One participant described waiting almost two months to obtain paperwork she requested to inform a supplemental insurer that Medicare refused payment for services received outside the United States. Another called her transition to Medicare “a heartache.” Some participants felt the information materials provided by Medicare are hard to understand and unhelpful when it comes to resolving “real-life” situations. There were some African-American participants who were happy with available information about Medicare. They tended to be beneficiaries who have not needed Medicare services or beneficiaries who have had no problems using their Medicare services. *Basic program information should be presented in common language and using devices that make it easy for beneficiaries to draw links between the information provided and their own situations. Examples and case studies may be useful devices. In addition, simple graphics may help beneficiaries understand important program features.*

Frustrations Getting Medicare Information
<p>“I had gone to Freeport, Bahamas... and I had a severe allergic reaction... to coconut rum. It was an Emergency Clinic where I went and the total bill was \$85, which was fine... Now Medicare is my primary, Blue Cross and Blue Shield is my secondary. So, generally when you go to the hospital or doctor they fill out your Medicare forms for you and do all the processing... In this instance, because it was out of this country, there was no such form available... [A]ll I wanted to know was, where do I get the form to fill out when I wasn’t in the situation that would allow it. Now the first thing they said was, ‘Well, we don’t pay for out of the country.’ I said, ‘I know that. That’s fine. All I want is the form so you can tell me you don’t pay for it so I can send the form to Blue Cross...’ And they were upset that I even wanted a piece of paper. You know this isn’t the way it’s done. But my point being that there is no consideration given to the exception.”</p> <p>“So when I got to be 63 years old I had to make that transition... it’s caused me serious heartache. So I would just like to share that with people about the kinds of inconvenience that this transition, going into Medicare, has been.”</p>
Participants with Complex Health Care Needs Have Difficulty Getting the Information They Need
<p>“But the way it [the Medicare program] is structured, unless you have someone who can really sit down and help you with it, I think for many people, they are disadvantaged because it’s not well stated and well taught. And even though they may send the information brochure, it becomes quite a different matter when they deal with it on a one-to-one basis in a hospital, say or something where everyone is in a hurry and I think they end up signing things... So I think, unless you’ve got a back-up for it, it can be an overwhelming experience, particularly if you are really sick, you’re really up a creek.”</p>
Participants with Straightforward Needs are Happy with Services and Information Available
<p>Moderator: “What information do you see as lacking?”</p> <p>Participant: “Right now there’s nothing happening to me. You know, I’ve got a little bit of everything, oxygen and everything else. I haven’t had any problems at all, yet.”</p>

Choosing a Provider

Most African-American participants reported that they rely on the recommendations of friends and family to choose a primary care provider. The same was true for participants from the general population of Medicare beneficiaries. Participants said that a list of providers' names and affiliations does not tell them what they really want to know—whether the provider can communicate with them and is genuinely concerned about their health. Participants assess a provider's interpersonal skills based on the experiences of trusted friends, family, and even their own encounters with health care professionals. A few participants said they would be interested in getting brochures and pamphlets from HCFA about choosing a doctor, but most did not think this information would be helpful. Many African-American participants said they rely on recommendations from their primary care providers to identify specialists. Some said they prefer getting a list of specialists from their doctors because ultimately the decision about who to see rests with the patient.

Friends, Family and Personal Experience are Preferred Sources for Information about Providers' Interpersonal Skills

Moderator: "Do you feel like you get the information you need to help you choose a primary care or regular doctor?"

Participant: "Well... it's sort of like you really don't know the doctor. You got to get to him to find out if you like him or not."

"I think firsthand information from someone who has had experience with the doctor is the best because they can tell you if the doctor is good at what he does or if he has good bedside manner or if he has compassion for people. You would take that into consideration, I think."

Moderator: "How did you get your information on choosing a doctor, or did you?"

Participant: "Recommendations."

Moderator: "Recommendations from whom?"

Participant: "Friends, other people."

Moderator: "In what form would you like to receive this kind of information [about choosing a doctor]?"

Participant: "Maybe word of mouth... Because if you get word of mouth, usually people will tell you something out of their experience and you go from there."

There Were Mixed Reactions to HCFA as a Source of Information About Providers

Moderator: "Okay. But would it be helpful to have more information about the doctors?"

Participant: "You mean about a doctor, for the agency that administers Medicare to provide information on a specific doctor?"

Moderator: "Yeah. Do you feel like that's something you need?"

Participant: "Personally, I would think not. I don't think they could possibly have enough knowledge about it to make an intelligent decision or reference and I would be suspect of a list that they had as opposed to some other list. And that's number one, I wouldn't trust it because I wouldn't know how everybody got on it. I think Medicare should stay out of the business of trying to choose a doctor. And I do think that's going a bit far."

Participant: "I feel the same way."

Participant: "I agree."

Participant: "The same."

Moderator: "So what if I just sent you all this information on brochures and stuff like that on how to select a doctor? Would that be something you would trust?"

Participant: "I would."

Participant: "I would."

Moderator: "But that's not a personal referral. Why would you trust that?"

Participant: "I mean, it sounds so good."

Participants Rely on Primary Care Providers to Recommend Specialists

Moderator: "Do you feel you get the information you need to help you choose a specialist?"

Participant: "I trust my doctor for that."

Participant: "I go to my doctor for that."

Participant: "I feel like if you have a doctor and... you pick a doctor, then you either like him or you don't. You trust him or whatever he says, that's my doctor... So, to me, if my doctor tells me, 'Well, I would suggest that you try Dr. Smith, he's the best one in his field...' Well, if you like him as your doctor and trust him... you'll trust what he's saying. Now when you go there, however... and you don't feel like this specialist is... Because I went to a specialist that my doctor recommended and I didn't care for him. And when I came back to him, I told him, don't send me back... because I'm not going. He said, 'Well...' and I said no. He didn't handle it right, to me. And I'm the one has to be satisfied."

"My doctor usually gives three names [of specialists] if you want him to and if you want to choose your own you can."

In general, African-American participants seemed comfortable relying on their own judgement, on their social networks, and on referrals from other providers to help them find providers they trust.

Medicare HMOs

African-American participants reported negative attitudes toward HMOs. The concerns they expressed were similar to those expressed by participants from the general population of Medicare beneficiaries. Many of them had heard “horror stories” about HMOs from friends and family members who were enrolled in HMO plans. Like participants from the general beneficiary population, African-American participants were concerned about losing the ability to choose their own doctors when they sign up with HMOs. Some participants said they quit HMO plans they joined after discovering restrictions on provider choice. Also, participants reported wanting clearer information about the costs associated with HMOs.

Negative Reactions to HMOs

Moderator: “Did you get a sense that you have enough information about [HMOs] to make a choice, rule them out, rule them in?”

Participant: “They frighten me.”

Moderator: “Has anyone even thought of it as an option, Medicare HMOs?”

Participant: “If I become unable to pay as I do now. I think that would be the only thing because I’ve really heard some horror stories about HMOs. Going to emergency rooms and you cannot be treated, being turned away because they can’t get the okay. I mean you’re sick and you’re hurting like that and here you are in an emergency room and you’ve got to wait for somebody to give you the okay and they’re going to make the decision, ‘Well, do I want to send her all the way across town in pain or can she be treated where she is...and most time they have their own hospitals where they want you to go.’”

Concerns About HMO Access to Care and Provider Choice

“I didn’t want an HMO because I have a friend whose husband has an HMO and he has to drive past the closest hospital to get to a hospital they recommend.”

“The main thing about HMOs is it’s so disheartening as far as you have to change your doctors... and then they said that you have to get rid of your doctors that you go to all of the time. I think it’s so senseless. To go somewhere all of a sudden and have to change your records and all of that, I just want to know why.”

“We joined [plan name], paid money for that and found out you can’t go nowhere but to their doctor and to where they want you to go. And, if you already have a doctor, you just forget about him and go to the one they want you to have... So I had to get out of there. That’s why I got to go back to Blue Cross.”

HMO Costs Make Them Attractive to Some Participants

“So with me not working and I had quite a few bills I just took the one HMO where I don’t have to pay anything a month...”

“The reason I want to know about HMOs is because my husband is in that and they don’t seem to pay the bills. They always charge him a whole lot for things and that doesn’t seem right. He pays the money, the premium for that insurance. He has high blood pressure and he’s on sugar pills and I mean his medication he has to pay a lot for.”

Supplemental Insurance

For the most part, African-American participants reported that they had enough information to choose their supplemental insurers. Participants reported that their employers were important resources for them in selecting supplemental insurance. Participants also relied on literature they received in the mail, from local hospitals, or AARP. A few beneficiaries reported that they did not play an active role in selecting their supplemental insurance. At least one participant reported becoming aware of the importance of supplemental insurance when the subject came up in a discussion about an upcoming operation. *While participants reported having sufficient information to choose a supplemental plan, it is important to remember that many participants seemed to lack basic information about the role of supplemental insurance and how important supplemental insurance is in obtaining adequate coverage.*

Employers Are Important Resources for Supplemental Insurance

Moderator: "What process did you use to choose which supplementary coverage you would take?"

Participant: "I'm a city retiree... [E]very year they have a list of different plans and options available... and you can choose and you can change once a year at these things if you're not satisfied. So with that pool, and they have meetings to discuss if you have questions, but everybody has the literature and that's how you make your choice."

Moderator: "So, now, did this come through your employer?"

Participant: "It came through the employer. Through the benefits office..."

"I retired from [company] so they had a very good insurance that picked up anything that Medicare doesn't. So I've never really had to search for anything else and that was part of my package deal for retirement and they pay my insurance."

Moderator: "And where did you get your information about those choices?"

Participant: "From the job."

Participant: "I got mine from... I applied myself... They'd send out letters just about every one or every two months, Blue Cross... This literature comes to the house."

Materials Mailed by Supplemental Insurers Are Useful Resources

"The packages that I told you I got about five different packages. I got it from the television, you know..."

Some Participants Learned About Supplemental Insurance Through Experience

"You have to have additional insurance and I didn't realize that until I needed to get an operation and they told me I had to get another insurance... It was my choice out of the book, but it wasn't of my choice as far as I was concerned."

Staying Healthy

According to the second Inventory Report, African-American beneficiaries tend to be less knowledgeable about preventive care and behavioral risk factors than other beneficiary subpopulations. Like general population beneficiaries, African-American focus group participants reported that they get enough information from a wide variety of sources on how to stay healthy. Participants reported that they do not always act on the information they have. Similar to general population participants, African-American participants complained that the information they have access to is often contradictory. For African-American respondents, the problem of sorting through conflicting information about staying healthy is more difficult because the information is generally broad, referring to general populations. One participant highlighted the difficulty interpreting information about general populations by noting that the medical profession is getting better at addressing health concerns that are specific to African-Americans.

There is Sufficient Information About Staying Healthy
Moderator: “Do you get enough information about how to stay healthy?” Participant: “[T]here is a lot of information out there that you could pick or choose from depending on what your particular condition might be.”
Moderator: “So you get that information, preventive services, from your physician?” Participant: “Yes. And plus, I mean, the newspaper, the magazines, television, you see it everywhere. Just like you said, once you get 65, you on everybody’s list. So you getting something all the time.”
“I feel like we get plenty information. Especially now that we are black, you know what I’m saying. You know, we have more high blood pressure and all of this and everything now is study group, you know. But, and I feel like that we get the information.”
Information About Staying Healthy is Confusing and Contradictory
Moderator: “Do you feel like you get the information you need to stay healthy?” Participant: “It changes so much. They say something is good for you and then next week it isn’t...”
“There’s too much information. It’s all confusing. First you can’t eat eggs and then you can eat eggs. I mean every time you look at the television or you pick up the newspaper there’s something about your diet and I think it’s too confusing.”
General Information About Staying Healthy is Difficult to Interpret
“I’m very negative towards a lot of the stuff where they... when they group people, everybody’s the same. This is good for you. That’s good for you. Eat this, you’ll live forever. You’ve got to accept the fact that people... each individual is different.”

Some African-American participants seemed interested in receiving information on healthy behaviors that is specific to African-American seniors. To reduce sensitivity, it may be most effective to present population-specific information in information that is developed for all seniors with specific messages tailored for each of several more specific groups.

Other Information Needs

African-American participants wanted to know more about the solvency of the Medicare program—how Medicare money is used and what is being done to preserve the program. General population beneficiaries also raised questions about these issues. Among African-American seniors, several sought information about why certain basic services like prescriptions, vision and dental care are not covered by Medicare.

Concerns About Medicare Solvency

“I’d like to know why they’re declaring bankruptcy all the time.”

“The thing that comes to mind is how long is this Medicare going to be able to support your personal health needs in terms of how much the deduction is at this point in time... [W]hen you think in terms of how much money that you as an individual contribute over a year’s time, let’s say, it doesn’t begin to compare with what Medicare might be reimbursing. The program provides a service. Well, I wonder how long they’ll be able to stay in business.”

Participant: “When the President’s budget is approved and when they get whatever balancing they said they did, I don’t know to what extent or when we will find that out, but I did hear on TV that they would take something from Medicare.”

Questions About Coverage Limits

“I tell you, I was waiting for this. I don’t understand... It’s a known fact that dental care and ability to digest and chew is a factor and it involves your whole being... To me, to omit dental care and eye care from a medical program to a senior group is ludicrous... prescriptions, eye and dental are things that, if you are concerned about our overall government supportive medical program, how can you leave those out?”

Moderator: “Is there some information that you would like to get and you just don’t get it anywhere?”

Participant: “A better understanding of why they pay so little toward the cost of the doctors, examinations, the tests.”

3.3 Major Findings for Hispanic Beneficiaries

Many of the information needs reported by Hispanic beneficiaries echoed those of the general beneficiary population. Hispanic seniors expressed a number of additional unique requirements. The most obvious is their desire for greater availability of Spanish-language materials, telephone operators, and health care providers. Hispanic participants’ comments also revealed basic gaps in knowledge about billing procedures and coverage that were less evident in focus groups with general population beneficiaries. For example, a large proportion of Hispanic participants seemed to lack a basic understanding of the role supplementary insurance plays in their health plans. These knowledge gaps are

consistent with Inventory Report findings that Hispanic beneficiaries are less likely to use health insurance before enrolling in Medicare than other beneficiary subpopulations. Hispanic participants asked detailed questions about false billing, how the billing process works, and which services are covered. Hispanic participants were careful consumers who needed clearer, more accessible information. *It is especially important to provide information in Spanish, and to disseminate Spanish-language information through an array of media and formats.*

Medicare Program

Most Hispanic participants reported infrequent contact with the administrative arm of the Medicare program. Several participants strongly asserted that they had no questions about the program. These participants reported either that they had no problems or that there was nothing more to know beyond the fact that their doctors submit the bills. Among the participants who identified specific questions, a few indicated that they made no effort to seek answers on their own. Participants who did seek answers often asked English-speaking relatives to obtain the needed information. This reliance on proxy information-seekers is consistent with Inventory Report findings that Hispanic beneficiaries rely on extended family networks for information.

Some Participants Reported No Information Needs

Moderator: “Now I would like for each of you to think back on when you have tried to obtain information about the Medicare program, any type of information. Have you made calls to obtain information?”

Participant: “I have never called anyone.”

Participant: “I have never called.”

Moderator: “You have absolutely never called?”

Participant: “No, no, no.”

Some Participants Had Specific Questions That They Have Not Tried to Answer

Participant: “This year, the first thing my doctor told me, ‘I want you to know that Medicare is not going to pay for this physical examination.’ I never received that information...”

Moderator: “Did you call?”

Participant: “No, I didn’t call. But the more I think about it the more I am concerned. You need that medical examination.”

Participant 1: “I receive enough money to pay for my medicine and to pay for the visit to the doctor.”

Participant 2: “I don’t agree with that. I get \$804. From that \$804 I have to pay rent, I have to pay electricity, I have to eat.”

Moderator: “Have you gone to any agency of Medicare to tell them that you don’t agree with that?”

Participant 2: “No.”

Information-Seeking Participants Relied on Proxies to Gather Information

“Well, I don’t look for information because if I need anything, my daughter is the one who gets moving on everything. So I don’t have any problems in that aspect.”

Moderator: “What kind of information have you tried to get recently?”

Participant: “I think it’s just when you need. I’ll go to my neighbors.”

Many participants reported making a phone call or visit to get questions answered. However, they were not sure who they contacted. A small number of participants reported using the Social Security office or brochures they’d received in the mail as resources. Participants who mentioned using mailed materials were unsure who sent them. Many participants remembered receiving the Medicare Handbook along with their Medicare card. No participants mentioned HCFA as a source of information, and most of them felt that the Medicare program does not send them enough information.

Participants Were Not Sure Who Sent Out Mailed Materials

Moderator: “How does the information reach you?”

Participant: “There is a brochure that one receives and signs to become a member of the program. When you retire, that information is sent to you and it contains information on what you need to do, who to write to, who to speak to.”

Participant: “Something came to me by mail.”

Moderator: “Who is it that sends it to you?”

Participant: “I don’t know who it is that sends to me.”

Moderator: “Who gave you this information?”

Participant: “There are people here, we speak about one thing or the other and we get this information. They should be a little bit more generous in their information.”

Perceived Link Between Medicare and the Social Security Administration

Participant: “...[S]ince I retired at 65 automatically they sent me my...Medicare card. And somewhere along the line, in the mail, I lost that card... So then I went to the office and they told me that that takes about two or three weeks in order to receive a new one. And in three weeks I didn’t receive it, so I had to request it.”

Moderator: “But where did you request it at?”

Participant: “...Medicare and Medicaid...”

Moderator: “But is it Medicare or is it Social Security?”

Participant: “It’s everything. It’s everything, because sometimes they mail you stuff or you have problems with Social Security, they will send you over there.”

Participant: “Social Security gives me a lot of information.”

Moderator: “And Social Security has nothing to do with Medicare.”

Participant: “But we don’t receive absolutely anything from Medicare.”

Moderator: “Who has received information on Medicare?”

Participant: “...They send me a card. Then when I go to the hospital, I give a card...”

Moderator: “What source do you think sent you this information?”

Participant: “Social Security.”

Many participants had questions about the Medicare program. They wanted more information about covered services. These needs were more basic than those expressed by participants from the beneficiary population, whose areas of inquiry tended to focus on the relationship among the different components involved in the Medicare program, and on explanations of the terminology used on Medicare billing and information materials. Furthermore, while at least one person in every Hispanic group asked detailed questions about coverage or billing procedures, discussions about how Medicare and supplementary insurance work together were raised only in an English-speaking Hispanic focus group. *Hispanic beneficiaries are likely to benefit from clear information about the services Medicare covers and the amount of coverage provided.*

Basic Questions About Coverage

Moderator: "What kind of information do you think you need that you don't have now?"

Participant: "What Medicare covers and what it doesn't."

Moderator: "Is there any Medicare information that you do not understand but would like to see more about this topic in the future?"

Participant: "Yes, I would. For example, it says there that one can go up to three times a year to the hospital, but I don't know how much it covers each time."

"I, for example, had to pay \$125 for this tumor. And I couldn't find out if Medicare was going to cover it or not."

"I was charged \$600 just for the [eye] appointment and I went back and I took in the card to them and now they say that they'll pay \$400 and I owe \$200. So I want to ask what this is all about because at least I consider this to be a lot of money for my eye appointment because I usually pay \$40-45 and now I'm supposed to pay \$200 out of my own pocket and I want to ask what is the reason for this?"

"I have one doctor that I went to see. I was so sick that they required me to pay the doctor, and then I had to get my money back from my supplemental. I think it shouldn't be done that way.... Yeah, that's what I've always felt... I've contributed one-third and the government puts in two-thirds... [I]t seems to me like if Blue Cross is getting \$400 a month from someone as a supplement, they should be the primary. They should be the one that's paying... And the ones that I'm paying less to, which is Medicare, should be the supplementary insurance. And why the government gets into this type of contract is beyond me."

"When I joined Medicare, I understood that Medicare now takes over the majority of the payment. And this is where I imagine that's a problem that we have here. We still pay the same amount, but now this thing is turned over where the government, which is us, the taxpayers, is paying more, yet... what used to be my primary, now I'm still paying the amount to them. So here, I feel there's something wrong there."

Participants also raised questions about payment centered on who should be paying for what and when payments should be made. Quite a few participants seemed confused about what Medicare or other insurance plans should be paying and what they themselves owe. Others had trouble sorting out whether they should pay first and wait for reimbursement, or simply submit the unpaid bill to their insurers. At least some of this confusion arose from language barriers between information-seekers and information providers. *Hispanic beneficiaries are also likely to benefit from information in Spanish about payment processes and how Medicare components work together to cover care.*

Questions About Claims Process

“I want to know if they’re paying me, I’m paying the doctor, or the doctor’s paying me. You can’t really tell.”

“But when we go to a doctor, Medicare does pay, doesn’t it?”

“...[I]ts been two years since I’ve paid and I haven’t been reimbursed at all.”

“I would like to know why it is that when one wants to go and see the doctor, it takes almost a month before you pay.”

Other information needs were specific to the Hispanic subpopulation. Many participants asked that Spanish-language written materials as well as Spanish-speaking telephone operators and case workers be more readily available. In addition, a few raised questions about how their own or their relatives’ immigrant status affects Medicare coverage and benefits.

Spanish-Language Information Needs

“For example, you know, maybe there’s a number that I can call and say, ‘Listen. I want all my papers in Spanish.’ Because I’ve requested it before in Spanish and they started sending it to me in Spanish. And I want numbers in case I can call. And that’s the way it should be.”

“If there is a change, I want to know about it, and especially in Spanish.”

“It would be great if it [information about Medicare] came in our own language, because my kids, they don’t know Spanish very well. And sometimes they try to interpret or translate and it gets all messed up.”

Questions Related to Citizenship and Immigration

Participant 1: "People always think that if you don't know English you're going to have your checks taken away from you, or your benefits or something."

Participant 2: "I was told that I have to become a citizen. And I have a friend who already became a citizen."

Moderator: "Are you applying for citizenship?"

Participant 2: "Yes... I guess I'm going to have to become a citizen because we're in this country and we're going to have to obey the laws, obey orders."

"I have a question. I have a brother who received his residency about six months or something like that ago. And I don't know if he can receive Medicare. I told him that when it was... when he had the time he should go get some information to clarify the doubt, because another brother emigrated. And I don't know whether he can get Medicare at all."

Choosing a Provider

Hispanic participants said they usually rely on recommendations from friends, family, and trusted health care practitioners to select providers. A small number of participants reported using health care associations or local hospitals to help them find a doctor. Hispanics who were fluent in English were more likely than their Spanish-speaking counterparts to conduct their own research when looking for a provider. Compared with general population beneficiaries, Hispanic participants were more likely to find providers through their clinics and less likely to identify interpersonal skills as important when selecting a provider. The second Inventory Report suggested an explanation for these observations. There is a higher rate of poverty for older Hispanics than for the general beneficiary population. Thus, Hispanics are more likely to receive care in clinics. In addition, older Hispanics have a high level of confidence in their doctors. Thus, Hispanic beneficiaries who visit clinics may trust the recommendations of clinic doctors and other health care staff more than expected in the general beneficiary population.

Friends, Family and Providers are Resources for Selecting Providers

Moderator: "How did you get your primary care physician?"

Participant: "Well, to me, I have a niece who can help me."

Participant: "Through friends."

Participant: "Well, it was through a recommendation of a sister-in-law, this is a sister who belongs to my church."

"Well, I chose him... because he studied with a brother-in-law of mine. And my sister said, 'Hey, why don't you go to see him?'"

Some Participants Relied on Hospitals and Other Medical Organizations

“Well, I don’t know how you call it. It’s an association that doctors belong to. They’re members of certain—the American Doctors Association, something like that, but you understand what I’m saying. And they’re members of this organization. And I think that influences me a lot.”

Participant: “I get my information from the hospitals. I’ve called and then I ask them if they’re board certified, how long they’ve been doctors, how many operations, and the whole thing. Then I decide. I say, ‘This is my doctor.’”

Moderator: “Who gave you the name of this primary physician?”

Participant: “In the clinic, then... the neighbor [told] me that this doctor was very good so I gave him a try.”

“Well, we’ve just been sent to the clinics and then they give you a doctor right away.”

To many participants, a provider’s ability to speak Spanish was a primary consideration. Proximity was also an important factor for some participants. A small number of Hispanic participants reported weighing the provider’s education and experience when making a decision. Most participants reported relying on their primary care providers to recommend specialists. *Hispanic beneficiaries seem comfortable relying on health care professionals for recommendations for new providers. Language is a more important factor than more general interpersonal skills. They seem most likely to benefit from information on providers with Spanish-language skills.*

Spanish Language is an Important Criterion

Moderator: “So usually you prefer that the doctor speak Spanish? Do you all agree that you would like for your doctors to speak Spanish?”

Group: “Yes.”

Participant: “For me, it’s very important that they speak to me in Spanish. I don’t care what their nationality is, and they could be perfect, but if they can’t speak...Spanish, I can’t.”

Moderator: “Why is that so important?”

Participant: “Because I can communicate.”

Moderator: “Well, how did you choose this doctor?”

Participant: “I would just go down the road where the clinic was located. And I went over and talked to somebody there, talked to the people who were there at the clinic. I asked them if they spoke Spanish, and they said, ‘Well, very little.’ So I asked if they would give me a Spanish-speaking doctor. And they found one for me.”

Convenience Was Important to Some Participants

“Basically, I’d like to get a doctor who lives closer to me. And that’s what I did.”

Participants Relied on Primary Care Providers to Recommend Specialist

Moderator: “As far as specialists, anything you’d like to know regarding a certain specialist?”

Participant: “Well, you know, just as long as he comes recommended.”

Participant: “You ask another doctor for an opinion.”

Medicare HMOs

Due to revisions in the moderator's guide, discussions about Medicare HMOs occurred only in the two English-speaking Hispanic focus groups. These participants reported that they hesitated to trust the care available through HMOs. A few participants spoke of friends or relatives who received improper care through HMOs, and many participants expressed concern because HMO providers are given incentives to discourage their patients from seeing specialists. Another major concern raised by participants is restricted provider choice under HMO plans.

Concerns About Restricted Provider Choice
Moderator: "Have you considered joining [an HMO]?"
Participant: "No. Everybody wants to choose their own doctors and have more control."
Participant: "That's the one I want. The one that lets you choose."
Incentives to Discourage Access to Specialists
"In an HMO, they pay the doctor a certain fee for a patient. And they have to stay with him. And then if that patient wants to go to a specialist, they try their best not to send you. Now, if he goes to a specialist and they spend more money than what they're entitled to, they get penalized. So they just do not give you the attention that you really need."
"I know people in my family who have had pretty bad experiences about the doctors that they're seeing will not refer them to a higher level of medical... [W]e know for a fact that that doctor is going to get a bonus if he doesn't refer over X number of people to go see a specialist further up the line. And I think that's something that the Medicare people really should look into, that HMOs are denying medical care to people who need it because they are giving bonuses to the doctors who do the denying."

Supplemental Insurance

Hispanic participants had diverse levels of knowledge and understanding about supplementary insurance. Some participants seemed to understand the options and how to get information about them; some participants were less informed but had trusted sources to whom they can turn for help; and some participants were confused about their options. The third category was most common for Hispanic participants. The Inventory Report noted that newly enrolled Hispanic beneficiaries often have little or no previous experience with health insurance, and this may account for the frequent confusion and generally low familiarity with terms like "supplemental insurance." Several Hispanic participants reported that they did not understand what supplemental insurance is. A few beneficiaries reported that friends or relatives assisted them in choosing their supplementary policies; others said they chose a supplementary plan based on company brochures they received and on presentations they attended. Again, access to Spanish language materials was important in this area. *Hispanic beneficiaries will benefit from clear descriptions of the role of supplemental insurance, how it*

fits with Medicare, and the options for supplemental insurance available to Medicare beneficiaries. This information about supplemental insurance should be presented in the context of more general information about the purposes of health insurance and how it works. Furthermore, all of this information should be available in Spanish.

Basic Questions About Supplementary Insurance
“What’s this supplement they talk about? What’s a supplement?”
“What’s the difference between supplemental and insurance? Supplemental to the insurance?”
Reliance on Information Provided by Insurance Companies
Moderator: “How did you choose that company?” Participant: “Well, they came to my house and they called me. And I liked them.” Moderator: “No one else tried reaching you other than that company?” Participant: “Oh, there were several companies, but, you know, they got to win you over.”
“Well, like I said before, I have two daughters. And they work at [a local hospital]. And, of course, they’re involved with insurance companies because of their patients or operations or whatever... [M]y daughters told me, ‘Listen, why don’t you wait. I’ll look into it. I’ll find out.’”
Spanish-Language Materials Are Important
“In my case, you know, they send information in English and that’s a problem.” Moderator: “How could I get you the information [about supplementary insurance]?” Participant: “Well, like they said before, they should send it in the mail. However, these pamphlets would need to be in Spanish in order for you to not have any problem in understanding it. Because you can go over it in English and you can get a main idea but otherwise you’re not going to know. I, for instance, don’t know any English. Every once in a while, they send us papers through the insurance in English...”

Staying Healthy

Most Hispanic participants said they get enough information about staying healthy. A few said they would like to know more about some topics, including diet and exercise, breast cancer, high blood pressure, diabetes, and prostate cancer. Unlike general population participants, Hispanic participants did not express concerns about having access to contradictory health information. Hispanic participants reported relying on their providers and the media, especially newspapers and television, for information about staying healthy.

Kinds of Information Needed
Moderator: "What kind of information would you like to receive that would help you to lead a healthy life?"
Participant: "Well, I'd like to know what to eat."
Participant: "Breast cancer."
Participant: "Well, for me as a diabetic, I know that I would need to have some information about that."
Participant: "High blood pressure."
Providers and Popular Media Are Common Sources
"Well, my doctor gives me some information. He tells me what I should put in my meals. He gives me information about what kinds of meals I should have."
"I used to take a lot of vegetables... eat a lot of vegetables and I walk a lot. I heard the information on TV."
"The only thing I get is, for example, on flu shots, when it's time, when it's the season for that. I get it out of the newspaper. I receive nothing in the mail from either Medicare or my supplemental insurance."

Other Information Needs

Participants reported that they want more accessible information about Medicare coverage. They also requested providers who accept Medicare patients, and better communication about changes in Medicare coverage and policies. Several participants also asked for information to help them identify and report overbilling and fraud. This result seems to conflict with Inventory Report findings which suggested Hispanic beneficiaries often don't understand the concepts of health care fraud and abuse. Hispanic focus group participants were aware of some problems related to fraud—especially fraud among service providers. For example, one group wanted Medicare to monitor home health care services more carefully. Participants reported experiences with ineffective and negligent workers through these services.

Needs for Basic Information on the Medicare Program and Coverage

Participant: "You know, I needed some kind of orientation."

Participant: "Yeah, that's happened to me... I didn't know if they were going to cover that. I didn't know where to look."

"You don't know, for example, what doctors accept Medicare in your area."

Participant: "They should send a pamphlet or a book... describing what changes they're going to make, because you hear that they're going to have changes. You know I'm scared about that they're going to take something away from me."

Participant: "Well, I would be interested in them sending me something. You know, tell me what they're going to cut, what they're not going to cut."

Concerns About Medicare Fraud

"I need more information. ...I received a bill and I notice that sometimes, like they put something more. Right now, they put two vaccinations, one for the flu and one for pneumonia. When the paper came, they were charging for three. Three vaccinations. I only received two."

Participant: "You know this home health care? I think some of the home health care people take advantage... [T]hey're not taking care of the elderly the way they're supposed to."

Participant: "They should report them."

Participant: "I think we should turn people in that are not doing work."

Moderator: "Maybe they should provide you with forms."

Participant: "A list of requirements of what they're supposed to do."

Participant: "Well, the referrals."

Moderator: "Maybe if Medicare had a recommendation?"

Participant: "That's what I'm talking about, because they're not aware of what these people are doing. They're just paying out."

Access to Information in Spanish

"Well, for me, it would be better if it came in Spanish. It would be easier if it could come in Spanish, because I know nothing about English."

"To me, it should be in Spanish as well because if they send it to me in English, I'm not going to understand. To me, it should either be a letter, a telegram, or some kind of notice. But right now, there are a lot of difficulties in wanting to read it."

3.4 Major Findings for Dually Eligible Beneficiaries

Like participants from the general beneficiary population, dually eligible focus group participants were generally unfamiliar with the Health Care Financing Administration (HCFA), and many of them associated the Medicare program with the Social Security Administration. *We have already noted that HCFS's shift in focus to customer service and satisfaciton makes it important to help beneficiaries recognize the services that HCFA provides.*

Perceived Association Between Medicare and the Social Security Administration
Participant: The government. Moderator: The Federal government? Participant: Yes. Moderator: Is there any particular part of the Federal government? Participant: Social security. Moderator: Who is Medicare? Participant: The government. Moderator: The government. Any particular part of the government? Participant: I think it's an insurance ... help pay the bill. Moderator: So it's health insurance from the government. Anybody know what the name of the agency is that runs Medicare for the government? Participant: Social Security. Participant: Social Security.
Low Familiarity with HCFA
Moderator: Has anybody heard of the Health Care Financing Administration? Participant: No. Moderator: It's the Health Care Financing Administration. Has anybody heard of that? Participant: No. Moderator: Ever heard of that name? Participant: No. Participant: No. Participant: No.

Dually eligible beneficiaries demonstrated a range of strategies for gathering information and different preferences for information delivery. Relatively many dually eligible participants seemed to be passive information-seekers. For example, dually eligible participants reported that one way to work with coverage they don't understand is to do what they want to and wait for Medicare or Medicaid to respond to their activities. Other participants reported a similar, passive information-seeking strategy, making use of forms sent by Medicare to start conversations with telephone assistance operators and/or health care providers about how to file claims and receive care. The following quotations illustrate a few passive information-seeking strategies that seemed unique to the dually eligible beneficiaries.

Unusual Passive Information-Seeking Strategies

“Well, I’m really sick of dealing with bureaucracies. I never, never, never call them. I go ahead and do what I need to be done and if they don’t do it, then they send me a form. And they send you a form saying you cannot do such and such and there’s a telephone number on the form.”

“Once you have a definite form, you can call someone and say, I just got a form saying.... And I call that number but if you go ahead and call and ask questions, nobody knows anything. You have to wait to get a form from the government that says, yes, you can’t do that and they always have a telephone number on it. So then you call them and you say I got this form, this name is on the form, this is what the form says, it’s time to get action. I never, ever, ever call the bureaucracy. I put the information on the form and send it back in.”

“At one point I assumed that Medicare or Medicaid paid for my crutches, wheelchairs, walkers, things like that. Well, I understand now that they will pay half. And the people pay the other half. I’m not aware of what is entitled to us, because I have not reached that area where my needs are that great....But, I’m sure I’m going to get there.”

Preferences for Reactive Information

“I’ve never had any problems with Medicare or MediCal. When I realized that Medicare, I had 40 or \$50 taken out of my social security plus I had to pay \$100 deductible plus 20 percent, I went down to the place on Keiko where you get general relief and food stamps and MediCal. I applied for MediCal there and I immediately got it and thus far I’ve had no trouble.... I’ve not asked them any questions. I have a problem which I have to go through every six months with USC. I go there, I show them my Medicare or MediCal card. I get in, have an exam, which I’m going to do again tomorrow.”

In addition, some participants who were satisfied with the services they received reported that as long as the systems were working smoothly, they did not need detailed information about how the systems work. We noted in the first focus group report that this attitude seems to reflect a preference for reactive information. That is, these participants seem to want access to detailed information only when they need it to address a problem or answer a question. *The relatively strong reliance on passive information-seeking strategies means that dually eligible beneficiaries are particularly likely to benefit from information strategies that involve diverse media, formats, and channels.*

Participants who were dually eligible for Medicare and Medicaid expressed some general concerns and needs that were similar to concerns and needs expressed by participants drawn from the general beneficiary population. For example, dually eligible participants were concerned about the future of the Medicare program, as illustrated by the following quotations.

Concerns About the Future of the Medicare Program

I have a lot of good things to say about Medicare. Come to think about it, it's good especially for older people who don't have the ability to make the money that the younger people do... I'm a little bit worried about what is going to happen to it now and that it might be depleted.

I heard on the radio, I think it was yesterday or the day before, that by the year 2004, it might be all gone.

Participant: "Well, he said a while ago that they want to cut it out and who knows if it's going to work or not if they take money out all of the time."

Participant: "If they're going broke or something like that. You hear that all the time."

Participant: "I'm worried about it. You're saying Social Security is going broke; is that correct?"

Participant: We don't know.

Participant: Nobody knows?

Dually eligible participants also expressed frustration dealing with program bureaucracies that were similar to frustrations expressed by general population focus group participants. These general frustrations are illustrated by the following quotations.

General Frustrations with Health Care Bureaucracies

I've been afraid to call sometimes.... Just stay away from them.... The answer they give you sometimes they don't help you; they make you upset.

I have had people who are really nice, they help you a lot. And I've had people who are not really thinking about the patient to talk of your problems

Well, I'm really sick of dealing with bureaucracies. I never, never, never call them. I go ahead and do what I need to be done and if they don't do it, then they send me a form. And they send you a form saying you cannot do such and such and there's a telephone number on the form.

"Once you have a definite form, you can call someone.... And I call that number but if you go ahead and call and ask questions, nobody knows anything. You have to wait to get a form from the government that says, yes, you can't do that and they always have a telephone number on it. So then you call them and you say I got this form, this name is on the form, this is what the form says, it's time to get action. I never, ever, ever call the bureaucracy..."

...And you got to go through a billion different stages to be able to understand it. You got to go through a doctor, a nurse ...

Some of the frustrations expressed by dually eligible participants seemed to be due to the fact that dual eligibles have to deal with at least two governmental programs in order to receive care. As illustrated in the following quotations, some participants reported having trouble finding a single source of information that could answer their questions. Others had difficulty identifying or articulating the types of information they needed.

Difficulty Identifying Single Useful Source of Information
“I stayed with [health plan name] and so I’m not going to go with an HMO. The people down at [my health plan] are very, very confused and not the brightest people in the world. The office people – about MediCal – they are totally at a loss about that. They can’t answer most of my questions.”
Difficulty Articulating Information Needs
I was looking for more information. I just don’t have an idea what can you get.

Important to provide information to dually eligible beneficiaries that is targeted to their unique need to work with two health care bureaucracies. It will be particularly important to identify the kinds of assistance available and how to access it.

Basic Program Information

Dually eligible participants had broad needs for basic program information—dealing with both Medicare and Medicaid. For example, participants asked fundamental questions about payment, claims processes and coverage under the Medicare program. Several participants seemed confused about whether Medicare enrollment was mandatory or voluntary.

Fundamental Questions about the Medicare Program
Moderator: If you can think of such an occasion, what was it that you were trying to find out and how did you try to get that information...?
Participant: I didn’t have any problem with it but I just wanted to know how to go about getting them to pay for my hospital bill.
Participant: I’d like to know why it became mandatory for me to become a part of Medicare once I reached a certain age. Let’s assume I had a good, what I considered to be, a good insurance that would pay. I guess it’s still doing—providing the payment, but why is it that it was meant that I would have to go on Medicare at a certain age.
Participant: I didn’t know you had to. I didn’t know—
Participant: You don’t have to.
Participant: No one ever—you don’t have to....
Participant: Okay. Well, then, what then is the advantage, and I guess that’s the question, you know. What advantage is it to me to become a part of Medicare over what’s considered to be a very good—what I had considered to be—I had it for 30-some years, you know. And then—and I guess I just didn’t understand. I thought it was automatic, you know.
Participant: You don’t have to go on Medicare, but if you had a plan the only thing you’d have to do is compare the monthly premium you pay, either your retirement or your wages that you made, compare that to the expense of Medicare.
“Given my particular situation, who is actually paying if I had a claim under Medicare, would my insurance at [my employer]... pay those? And that’s the way I understand it now....”

Participants had equally fundamental questions about the Medicaid program and what it covers. Some participants reported they have never received information about the Medicaid program, other participants were not sure how to access services under Medicaid, and others didn't know whether they paid for their Medicaid coverage.

Fundamental Questions about the Medicaid Program
<p>"I've never gotten anything from MediCal thus far."</p> <p>"Is MediCal free of charge or do we have to pay?"</p> <p>"Does Medicaid have a medical card?"</p> <p>"I just recently found out that I don't have to pay. They sent me a black and gold card. I'd really like to ask some questions about it because I don't understand how I'm supposed to use it."</p> <p>Participant: Why don't Medicaid put us out a book like Medicare does...?</p> <p>Participant: Medicaid does not send a book like Medicare.</p> <p>Moderator: So you would want a separate booklet on Medicaid in addition to the booklet you get on Medicare...?</p> <p>Participant: That would explain what they do and what they don't do just like Medicare does.</p>

The basic questions asked by dually eligible beneficiaries reveal important gaps in information about each program and about how they work together. Since Medicaid programs vary across states, it will be important to determine whether information about both programs should be provided together from a single source. If a single source is desirable, then it will be important to identify effective information partnerships that provide basic information that may be state-specific. It will also be essential to develop creative methods for delivering this information to beneficiaries who are likely to be passive information-seekers. Some of these issues are good candidates for survey data collection efforts.

A few participants had specific questions about criteria for Medicaid eligibility. These participants wanted to know which payments and which assets were included in calculations of earned income. They reported that they had trouble finding answers to their questions, possibly because their questions were too detailed for the information resources they contacted.

Questions about Medicaid Eligibility

“...I have a part time job and I tried to find out... because I’m paid for the number of miles. And I called and asked them ...would it be taxable and would it count against the money I draw—would it count against the quantity they allow you to earn per month. And they had a list. They weren’t sure. One of them [at] an 800 number, took quite a while and read the list and came back and told me she was not positive. I ought to call the local office and see what they say. So I did...

“They said they have a list of items that were taxable... They said if they take Social Security out of it at your work place, then they would count it against me as earned income, but they weren’t positive. So they asked me to call the local office.”

Some participants seemed to have a clear understanding about their coverage under Medicare and Medicaid, the different functions or roles of Medicare and Medicaid, and how the two programs work in concert to cover the services they receive. However, there were many more participants who were confused by the programs’ components and about how the programs work together to provide coverage. This confusion seemed to be a major hurdle for dually eligible focus group participants who wanted to understand their coverage and how to use the two programs effectively.

Clear Understanding about Medicare, Medicaid and the Relations Between Them

“...I have a card that says, you know, Medicaid participant. And I don’t pay for my Medicaid. The state pays for it. So therefore, all the bills are sent to the state.”

“The way that I understand it, is when you get your bill, you get... like, mine says hospital and medical. The hospital is part A and the medical is part B.”

“Federal is my number one. Wherever I go when I put [Medicare] down. I put it down as number one and the state is number two. I guess it takes over when the Federal don’t.”

“One is for the hospital and one is for the doctor.”

Participant: the way that I understand it, is when you get your bill, you get—now, like, mine says hospital and medical. The hospital is part A and the medical is part B....

Participant: If I wanted to get a prescription, I can’t use this card. They won’t pay for it, but I can use this....

M: Is it clear to you the difference between Medicare and MediCal as far as who they are?

G: I believe MediCal is state and Medicare is nationwide.

Confusion about Medicare and Medicaid

Participant: All I know is I had an A and B.”

Participant: That’s different, isn’t it? A and B, that’s Medicaid, isn’t it?

Participant: I am a little confused about Medicaid and MediCal.

Moderator: Does anybody else have that confusion, Medicaid and [Medicare]?

Participant: Medicaid is the one that pays for your medication.

Moderator: Well, there’s Medicare and there’s Medicaid. Now that’s an interesting point. Are you clear on what the difference is between the two?

Participant: Medicare, I assume, takes care of the doctor. Medicaid takes care of the medication and the hospital bills.

Participant: Medicare takes care of the hospital, but Medicaid takes care of the doctors.

Basic information developed for dually eligible beneficiaries should give overviews of the Medicare and Medicaid programs, the goals of each, and how the programs work together to cover health care. Components of the Medicare program should be identified and distinguished from Medicaid. This basic information should focus on functional relations between program components and functional distinctions between them. Concrete examples and graphical devices may be particularly effective methods for conveying basic information about Medicare and Medicaid.

In addition to general questions about the functional differences between Medicare and Medicaid, dually eligible participants had a variety of relatively specific questions about the relations between the two programs. Some of their specific questions were related to coverage—both the limits of coverage under the two programs, and which program pays for which kinds of care. Questions about which program pays for which care touched on a second set of specific questions dealing with payment and claims processes.

Questions about Coverage Limits

“Well, I would like to know if you’re a long term patient of cancer or some kind of disease that’s long term, you know, would they still help you or for how many years would they help you and stuff like that....let’s say cancer or something like that, that doesn’t—myself, I had an accident at work. And I’ve been through that, you know all this time. And they have never refused me anything at all. But I was wondering if, like, chemotherapy and all that stuff, would they help, and for how long.”

Is there a limit as to how much Medicaid you use for that sort of a person that’s sick constantly, or in and out of the hospital a lot, and things like that? Is there a limit?

Participant: It explains that it that book.

Participant: It does?

Moderator: They call it durable medical equipment.

participant: “...senior citizens, housekeepers, nurses aids. Is this an issue also?”

Moderator: In whether this is covered?

Participant: Yeah.

Moderator: Okay. That’s something you’d like information about.

Participant: Yeah. And you got to go through a billion different stages to be able to understand it. You got to go through a doctor, a nurse --

... And also my medication. There’s two allowed each month, but if your doctor will apply for it, you can get more if you have to have more. You know, a lot of people take five or six medications a day. I don’t take any.

Moderator: And what I’d like to know is do you feel that you have enough information about the Medicaid side of your health plan?

Participant: I mean, I think I would like a little bit more information as to, you know, like I asked a while ago, what’s the limit on Medicaid, you know, and things like that.

Questions about Which Programs Covers Which Care

Recently I was in the hospital and I—the first time in my life I got a notice from Medicare saying this is not a bill. So I just looked at it and assumed that Medicaid would take care of it.

Participant: I thought Medicaid was for when you were in the hospital. Medicaid took care of that and Medicare took care of the doctors.... prescriptions

Participant: Medicaid pays for the medicine. And Medicare pays for your doctors and your hospital bill.

Participant: I disagree.

Participant: I disagree with that....

Participant: Medicaid pays for the doctors, plus pharmaceutical—your prescriptions, a few other things.

Payment and Claims Processes

But this is what I want to ask you. I want to get this clear. Now, if I go to the doctor, later on I'll get this statement that says this is not a bill and it will tell you how much Medicare has paid, or approved, but still in the next column it will tell you about what Medicare didn't cover. Is that paid by the Title 19, because I don't get a bill for that column there, in that second column.

And another question, another statement.... Now, I'm wondering, I had the statement the other day saying this is not a bill, et cetera, and they had that little part there, a part that Medicare did not cover. And I'm wondering ... whether that comes out of my pocket or not. I haven't gotten a bill for that...

I had called to ask about a bill, about how do you get the bill. They send out a form telling us what they have paid to different doctors for us. And one was refused....

It was resolved, but it was not—yes, it was resolved after a while, because they did. They really were supposed to take it, but somebody just read a chart and said I wasn't qualified for that particular thing. And I was.

Thus, dually eligible beneficiaries need relatively specific information about their own coverage and how their care will be paid for. Some of this information varies by state. Again, it will be important to identify the best resource for this information and effective partnerships for providing it. Some of this coverage information may be person-specific. The Synthesis Report from this market research project should identify effective methods for conveying person-specific information to dually eligible beneficiaries who are likely to be passive information-seekers.

The Medicaid spend-down concept was another source of confusion and specific questions. A few participants seemed to understand how spend-down worked. Many more participants were confused about how spend-down worked and how spend-down amounts affect payments for medical care. As illustrated by the following quotations, some participants wanted more information about how spend-down works. Others seemed to feel cheated by spend-down policies.

A Few Participants Seemed to Understand How Spend- Down Works

It's very hard on a fixed income, but when they have the secondary insurance like these people ... it's a different thing. You see what I mean? And they give you a certain amount that you have to spend before they will reinstate you.

Participant: I want to ask you a question. When you were notified of your spend-down, did they give you a certain amount that you have to spend before you're reinstated?

Participant: That's what they say

Many Had Questions Or Needed Information About Spend-Down

The knowledge of spend-down own just came to me four days ago. I was not aware of this procedure—had no knowledge of it, and would like to question it, as to why this last October, we were supposed to go into co-pay....

Participant: So my spend-down won't be over until February. It started in November, November to February. Whatever has to be paid for on the Medicaid part, I have to pay for it out of my pocket...

Participant: And this happens twice a year.

Participant: ... When my spend-down is over. And when I saw this money that Medicare did not cover for my doctor, I'm wondering if I'm going to get a bill for that...

Moderator: So you're not sure how the spend-down works and what you're going to have to pay.

My social worker said I was going to get a MediCal card so that would take the place of [insurance plan] ... She said this one can't ... medicine and whatever. So I'm not familiar, really, with the spend-down. I mean, what are they trying to do about us ...?

Participant: How do they determine each individual, how much the spend-down is? ...

Moderator: Okay. So I think we've identified one area where you're a little lacking in information.

Participant: That's major.

That's what they say... we got the state card. But we've been on the spend-down now for the past three years, and we've never paid a cent... according to the state, we get a certain amount—they go on, as far as I can understand it—by what you make a year.

Medicaid spend-down policies may be an area outside of HCFA's domain. It is important to note at least one lesson from participants' questions and comments about spend-down. In all information, it will be important to identify methods for explaining policies and procedures that clarify how they serve HCFA's beneficiaries. When beneficiaries feel cheated by or wary of policies and procedures, the policies and procedures should be revised, re-articulated, or reconceptualized.

Choosing a Provider

Dually eligible participants were similar to participants from the general beneficiary population in emphasizing the importance of personal characteristics, such as honesty, and interpersonal communication skills in selecting primary care providers. They were also similar to participants from the general beneficiary population in their reliance on primary care providers for recommendations about specialists.

Provider Selection Criteria
Personal Characteristics and Interpersonal Skills are Important for Primary Care Providers
Moderator: What kind of information would you like? Participant: Whether they are honest or not. “A friend of mine, you just get their name and you don’t know what they look like, and he tried to make an appointment because he wanted to talk to the doctor face-to-face. The doctor wouldn’t make the appointment so he called the second one that was on the list and now he’s with them because he wants his questions answered and the first doctor wouldn’t answer him. He said he was too busy.” “The company I worked with before I retired, their medical plan had the same doctor and dentist. So when I retired and went with Medicare, I didn’t have to change so I found it very simple. I’ve been with him for 10 years now.”
Primary Care Providers are Resources for Information About Specialists
Moderator: How about choosing a specialist when you need one? Participant: I can get any of that from my doctor... and if he can’t take good care, he recommends another doctor to do the job.... Moderator: So you just rely on your regular doctor.... Participant: Same with me. They refer you to who they want you to go to. They call them. They make the appointment, you just go. “... I see a family doctor. He will refer you to another doctor.”

Dually eligible participants seemed to have more trouble finding providers who would accept them as patients than participants from the general beneficiary population.

Difficulties Finding Providers Who Accept Medicare and/or Medicaid Patients
<p>“No. You got to call half a dozen doctors before you find one that will take a Medicare patient...”</p> <p>Participant: Yes, ma’am. I called at least four doctors and we had our quote of Title 19.</p> <p>Participant: Said they got enough patients.</p> <p>Participant: I went to a dentist He quite Title 19. He couldn’t take me any more, after I had been his patient for a year or more.</p> <p>Moderator: So that’s some pretty basic kind of information, is where can you find a doctor to accept the payment.</p> <p>“And they won’t take Medicare patients.”</p>

In the area of choosing a provider, dually eligible beneficiaries would benefit from information resources that can help them find providers who will accept them as patients.

Information about HMOs

Dually eligible participants varied in familiarity with HMOs. Some participants were familiar with HMOs and understood how they differ from other provider structures. Other participants reported that they received materials from HMOs but were not necessarily clear about what HMOs were offering them. Others seemed to be unfamiliar with HMOs. The following quotations illustrate the diverse levels of familiarity with HMOs.

Broad Differences in Familiarity with HMOs
<p>Moderator: Do you know what I’m talking about when I say HMOs, have you heard about them?</p> <p>Participant: They send different ones in the mail to you.</p> <p>Moderator: Have you heard of these kinds of plan? Just by a show of hands.</p> <p>Participant: Oh, yeah.</p> <p>Moderator: How many people have heard of these kinds of plans?</p> <p>Participant: Many, many, many, many, many, many times.</p> <p>Participant: What’s HMO?</p> <p>Participant: An HMO is a health group that has their own list of doctors which you go to... You go to those doctors. They will pay, generally, 90%. If you go to someone outside of theirs, they will generally pay only 70%.</p> <p>Participant: Which you have to pay. And you have a premium to pay monthly. It’s an insurance policy, but they are grouped together. They have their own hospitals. They have their own doctors, and they’re listed. It’s a group.</p>

Midway through the focus group research, we revised the moderator's guide to elicit more detailed information about information received about Medicare HMOs and whether these participants, selected because they do not belong to HMOs, have considered joining or switching to an HMO. Some participants expressed interest in receiving more information about HMOs, but most participants reported that they already receive a lot of information from the HMOs. When the moderator asked whether they have considered joining an HMO, reactions were generally negative. Some participants reported that they have not considered switching because they are happy with their current arrangements. Several participants reported anecdotes about bad experiences with HMOs to illustrate their concerns about the care they would receive. Focal concerns were inconvenience, long waiting times, and reduced access to providers.

Considerations in Switching to HMOs
<p>"Well, I'm getting everything now so why should I change over? If I changed over, I would lose everything."</p> <p>"My next door neighbor was telling me he was in an HMO. He would wait in the doctor's office for four or five hours."</p> <p>"I have a girlfriend that is in an HMO. And sometimes she has to wait 3 or 4 weeks for an appointment. You have to wait for an appointment with those doctors."</p> <p>"And when you get down there, when you get down there, you don't see the doctor you made an appointment with more than once a year. It will be somebody else every time."</p>

Dually eligible beneficiaries were not particularly interested in receiving more information about HMOs. At the same time, their comments suggest that at least some dually eligible beneficiaries lack basic information about how HMOs are structured and how they operate under Medicare and Medicaid. They may also lack objective information about the costs and benefits of HMO service. While they are not actively interested in receiving information, they might benefit from unbiased information about HMOs.

Staying Healthy

Participants mentioned a variety of sources for information about ways to stay healthy, including senior magazines and newspapers, AARP bulletins, and their health care providers. Focus groups participants in the general population groups expressed frustration about the large amounts of conflicting or changing information that they have access to about ways to stay healthy. This was not an obvious source of frustration among dually eligible participants. The group discussion seemed to serve an

educational function for some participants who were not aware of the types of information available to them about ways to stay healthy. One participant noted that low reading levels seemed to be an important barrier in accessing information on ways for staying healthy. Providing information on ways to stay healthy through diverse media may be particularly important for dually eligible beneficiaries.

Thus, dually eligible beneficiaries are likely to benefit from information on the resources available to them about ways to stay healthy. It will be important to identify resources that provide information in a variety of formats and media so that low reading levels are not a barrier. In addition, because of the prevalence of passive information seeking strategies, it will be important to disseminate information about available resources through channels that dually eligible beneficiaries are likely to encounter without making any extra effort.

3.5 Major Findings for Rural Beneficiaries

Information-seeking strategies reported by rural participants were similar to and as diverse as those reported by participants from the general beneficiary population. A large portion of rural participants seemed to be proactive information-seekers who were motivated to anticipate their information needs. A smaller number seemed to be reactive information-seekers who preferred to receive specific information when they needed it. The rural participants included many who seemed to be passive information-seekers—beneficiaries who used information that was sent to them but who did not explore additional resources. There were also several participants who seemed to lack any information-seeking strategy.

Diverse Information-Seeking Strategies

Proactive Strategies Were Common

“.... I remember I read some of it in an article.... the girl in the office of the dentist was going to charge me full price for everything they did. And I said, ‘Uh-uh.... I just read an article that Medicare does cover for surgery on dental work.’”

“It really tells you on there what you’re going to owe your doctor, even though it does say this is not a bill. So if I’m waiting around too long to get my bill from my doctor, I just take the Medicare form out to the office and get it out of the way and pay it on the Medicare form. And if I get the bill from the doctor later, I tear it up and throw it out. So I mean, it’s very simple for me.”

“... when I had some dental work done,... I assumed that the girl in the office would know ... what I owed [She] thought it was [not] all paid for. So fortunately I had read someplace that it was. So she said, ‘Well, I’ll send it in the way you’re stating it,’ and it came back that they did pay for the surgery.....So if you don’t get it from your office girl, try to go another step further, because they don’t always know.”

“I think that we should be made a little more knowledgeable before we retire as to what Medicare is... Well, I knew what it was on account of my health insurance, but the ins and out and the ups and downs, I didn’t know a thing about it..... It seems to me like you have to be made aware sometime previous to going onto this program of what you’re getting involved in, what your benefits are and all that.”

“You can ask your doctor before you even go if they accept Medicare.”

Last year—my husband and I were invited to one of the motels to a meeting that was being sponsored by an insurance company... they talked about the Medicare... And also, then they brought up what they could offer you, you know, as a supplement. And we received a lot of information there.

Reactive Information-Seekers Prefer Focused Information

“...When you’re trying to get information, you don’t want a lot of side information. You don’t want if this or if that. You want to know an answer to a specific question without hearing a lot of things you don’t need to know.”

Passive Information-seekers Use Available Information But Don’t Seek Additional Information

The only way I got information was from statements come back where they had paid and so forth.

Moderator: And have you gone anywhere to get information?

Participant: Just dialing the Social Security office.... I’ve never heard of any other place I could get the information.

Some Had No Strategy for Gathering Information or Identifying Resources

Moderator: What were you looking for, the name of a medical dentist?

Participant: No, just what they would pay and what options I had. And they—as far as I remember, they said dental work wasn’t covered, but particular dentist work might be covered.

Moderator: Where would you like to get that information?

Respondent: Anywhere they could give it to me. I really don’t know where I could get it.

“Well, I tell you I have no information.”

Participants' information-seeking strategies seemed to overlap with their preferred levels of involvement in Medicare claims processes. Some participants preferred high levels of involvement in claims processing, while others preferred as little involvement as possible. Participants who preferred high involvement seemed to rely on the EOMB forms, and they noted that EOMB forms would be more useful to them if the codes were easier to understand and if the forms provided more detailed itemization. From participants' comments, it was not clear whether more detailed information on the EOMB form would be useful for participants who preferred low involvement but had occasional questions.

Some Prefer High Involvement With Claims

"Well, we get that form that this is not a bill.... I always recheck mine.

"I did that this morning.... I went in May, and I have not received the disavowed bill. So I called Medicare this morning, the 800 number and she would send me a duplicate of it.

"And when you get the bill and it says code and then your insurance is following up. You know, it's like trying to read Greek.... I like to keep track of things to know what's going on. ... That's complicated, and that's the reason I didn't call... How do you follow-up when you don't know what in the world you're talking about. It's so confusing."

Participant: ...They don't itemize things....

Moderator: So you'd like more details about what's done so you can track it.

Participant: More accountability ...

Some Prefer Minimal Involvement With Claims

Moderator: But it sounds like what you're saying is, that when it works smoothly, you don't have a lot of questions.

Participant 1: Right.

Participant 2: It's really because they're paying the bills.

Participant 3: They pay the bill.

Participant 4: And that's wonderful.

"... Most of the time when I get a bill, ... my supplement pays for it. So I just don't—I guess I'm lazy. I don't dig into it... but I do look at my bills sometime and get sort of frustrated because I feel like I'm—feel like the hospital's charging for things that they don't do, and overcharging me for the things that should be on there..."

Layered information about claims will be particularly important for these beneficiaries with diverse information-seeking strategies and different preferences for claims involvement.

Several participants reported relying on their providers as resources and advocates in the claims process. This strategy was also reported by participants selected from the general beneficiary population.

Doctors are Trusted Resources and Effective Advocates in Claims Processing

“Well, Medicare, of course, paid the hospital part of it. But then I got the bill from the doctor, saying he’s not a participant. And it was quite sizeable. So I said, man I can’t pay all this. So... one of the girls in his office says, ‘Why don’t you contact Medicare. They have sort of a claim, a hardship claim or something like that.’ So I called the 800 number to tell the situation And in no time, they paid the whole bill.”

And I asked him what kind of insurance card, or what did he accept and he said, ‘Whatever you have.’ I said, ‘Okay. I have Medicare and Medicaid.’ He went in there and he worked on my feet and I came back out and I started out the door. And he said, ‘Just a minute. Come back here. You got to pay for this.’ He said, ‘Have a seat. I’ll show you how doctors are. Have a seat.’ I sat there about 10 minutes and finally he came back. Oh, we got it all covered now. They can do it.

“I also get my information from [my doctor]. He tells me how much—the percentage that Medicare will pay of my bill.”

Participant: They must have people that decide what a certain procedure is worth.... I’ve called a couple times... they say “We do not consider this test necessary.” Well, that’s odd. I had cancer back in 1991. I had a cancer operation. I had to go once a year for checks ... They said ... “We do not consider this a doctors office.” I mean, they turn it down three times, two or three times, then they pay it.

Moderator: And it sounds like you went to the doctor.

Participant: Right. That’s what I do. I just let him handle it. And the hospital the same way. I just call him and that’s the best way, because they’re more, I think, able to handle it, not deal with them as an individual.

One participant was particularly articulate about the value of and need for information that is tailored to individual situations and needs. Another noted that information about available information resources is particularly valuable.

Value of Situation-Specific Information

Participant: I think if you ask the person ... their status and before you answer the question. In other words, you have to put in the system the status of the person asking .. a question....

Moderator: That’s a very good point. What you’re talking about is a tailoring of the information so that it’s geared to the person who’s asking it.

Participant: Yes. It would save a lot of unnecessary complications.

Participant: I like that.

Information about Available Resources

...When I retired.... They didn’t give me all the information, but they did tell me where I could go to get additional information.

Basic Program Information

Some rural participants seemed to lack basic information about how the Medicare program is set up and how it works. As illustrated by the following quotations, participants seemed confused about the relations between Medicare and Social Security, about the roles of different companies in paying their Medicare claims, and about what they should do when doctors bill for more than Medicare will pay. This lack of basic information about the Medicare program may be related to some perceptions that the program is extremely complicated.

Needs for Basic Information about the Medicare Program

I would like to know what your deductible is for Medicare? I have never seen that anyplace. I've never seen, your deductible has been met.

I'm not even sure what company pays the Medicare here.

Participant: Excuse me for a minute. They pay the claims for Medicare?

Moderator: Right.

Participant: I haven't dealt with this that much so I don't know. I thought that the money came out of my social security.

Moderator: It does. But to actually process the claims [HCFA] enlists an agency for Medicare that contracts with insurance companies. But, the money does come from your social security.

Participant: With all due respect, we've had claims paid by two people, one from Blue Cross and the other by Prudential.

Participant: Wait a minute. When you go to a doctor and they charge you a high visit and then Medicare denies all that amount of money he charges, what happens, he doesn't get reimbursed?

Participant: You get a bill, that's what happens.

Moderator: So what would you like to know...? What can the government tell you to help you out with that?

Participant: I'd just like to know why they don't pay it, I guess. Why do those doctors overcharge since Medicare will deny their payment?

Participant: Sometimes I get this form and it says it's a Medicare write-off and I am not obligated to pay this amount. If Medicare has already paid their 80 percent and the supplementary insurance has picked up the balance, then what is this?

Participant: Hospitals do the same thing. If the doctor accepts Medicare and they charge you more, some people pay it. I know people who pays the difference. But if they accept Medicare, they have to by law, have to write off that debt.

Participant: But you see some things and they say you are responsible for that and you feel like a dog and feel like maybe the doctor won't be nice to me the next time.

Moderator: It seems like you need a little more information about how that part of the system works. Maybe how your responsibility fits into it so that maybe you don't have to feel so bad.

Participant: I think it's more how it's billed...

Some Seemed Intimidated or Frustrated by Medicare Complexities

Participant: It's just too complicated and too many variations.

Participant: Exactly.

Participant: I don't see that there is any complications.

Participant: Of course there are. One surgeon or doctor may charge \$80 or another \$120.

Participant: Yes but Medicare strictly says how much they will pay....

Participant: Is there any way to regulate the agency charges.

Participant: Well Medicare does have a set figure on what they will do for each one. But the problem is this and if you ever did that you sign a paper when you go to the doctor or hospital or what have you. The paper states that you will be responsible for the charges. If Medicare only pays \$500 and the doctor charges you \$650 you are responsible for the difference.

Participant: We're talking about ... one policy, covering all individuals, regardless. We don't have different billing, different discrepancies, different "don't pay this, pay that." There should be a comprehensive coverage. A control, if you will...

Participant: Medicare is inconsistent with what it will provide.

These results indicate that rural beneficiaries, like several other beneficiary groups, will benefit from general information about how the Medicare program is structured and how components of the program work together to cover beneficiary health care needs. This information should be layered to meet the needs of beneficiaries with diverse information-seeking strategies. It should also be available in a variety of formats to enhance understanding. Graphic devices, comparison charts, concrete examples, and small seminars are alternative formats that may communicate information to beneficiaries with different information preferences.

Participants identified a few specific areas where they would like additional information, including information about covered services and Medicare eligibility.

Some Specific Information Needs

Medicare Eligibility

Medicare seems to think I am still employed. I'm a consultant but I do not have permanent coverage and I fought the whole year for coverage.

Coverage and Benefits

"I wanted to get something on teeth and eyes, if any part of it was covered."

"...I found out through Medicare that they do take care of surgery, if there's any surgery connected with teeth, like jaw work or something like that. They do cover it. And if you have an operation for a cataract, they do cover the operation for cataract, and glasses for cataract."

[My] wife had a serious illness. And I wanted to know what I was entitled to.

In contrast with results from focus groups with participants from the general beneficiary population, rural beneficiaries seemed to have an understanding of Medicare assignment and how to work with providers who do not accept assignment.

Understanding about Assignment

And he got \$254 back from Medicare to pay on the doctor I went to. He said, right there's the sign that says I do not participate in Medicare.... I said, "Well, my bill's paid in full. You signed the bill." I just walked out. But you can force them. Either that or don't get paid.

Participant: ... I had been going to a doctor and he didn't participate in Medicare. So I had to pay him the full bill that he asked at the time of that visit. But he still has to send the claim into Medicare anyhow. So Medicare turned around, which is the way they do it, they sent me the 80%.... Because I had already paid it. So I didn't pay the whole thing. They send me the 80% that I paid him.

Participant: ...My one doctor does the same thing. I have to pay him when I go into the office, the full price. And then send it into Medicare. And then Medicare reimburses me 80%.

You can ask your doctor before you even go if they accept Medicare.

Participant: I think that is important, that you select a physician that is a provider. And then he is supposed to accept, you know, whatever Medicare says they will pay....

Participant: The statement says that you don't have to pay them, you know, if it's above what Medicare says they will pay.

Choosing a Provider

Participants mentioned a range of criteria that are important to them when selecting a new provider. Criteria included information about the provider's performance, willingness to make referrals to another provider, interpersonal skills, and the provider's hospital affiliations.

Provider Criteria

"...Trying to get information about one doctor is difficult.... So, if you're going to find out something, find out who has malpractice suits against him. That's unavailable too. Who has botched something. Impossible to find...

...If you need him [and] he feels he can't handle it, he will suggest that you get another doctor and I like that.

I want a doctor that knows me. I don't want to have to go to a strange doctor.

Participant: One that has compassion and heart.

Participant: I like a doctor that when I need to talk to him will return your call.

Participant: A doctor who at least makes an effort to learn your name.

If you have a doctor and you want to go to [a particular hospital], he ought to be able to treat you [at that hospital].

Moderator: So it sounds like around here there are special dynamics involved in picking a doctor. It's not just picking a doctor...

Participant: You're picking a whole medical—

Moderator: —team.

But now, hospitals are actually employing the doctors. They're working for the hospital.

A few participants noted that it can be difficult making trade-offs among competing selection criteria.

Difficulty Making Trade-Offs

Yes... in speaking to other people, other senior citizens who have had similar surgery... there are a number of them, and each has a reputation so she has ... a choice but then again, we have also heard negative reports about respective doctors so again, we're still back where we started--square one. We're not sure which one....

Participants mentioned several resources on information that would be useful in selecting a provider. They included hospital referral services, providers' patients, and other providers.

Sources of Information for Choosing a Provider

Participant: I had a reference from a doctor I had. I had a good reference.

I left my family doctor in Baltimore. And I didn't have any. And I had to go to the hospital....and I need one up here, so they gave me several names of what they thought were good doctors and would probably be available. So that's where I got my doctor.

Well, couldn't call you call the hospital or call the medical board at the hospital and ask the doctors they have...?

Well... I guess some medical societies put out a service where a stranger in town could call for a particular skill.

Probably some of the best recommendations are from people who have used them before and can recommend them. ... He was recommended by the internist there while my wife is laying in the hospital. In the emergency room, that is not a good time to start making choices and going around.

... My best experience has always been to call... A good hospital and ask them for a referral. I've had good experiences with that. But you have to understand, I'm sure that they will be talking to the people they are familiar with and who practice in their hospital.

I still like the recommendations from people who have used doctors.

Moderator: So these are the kinds of things that are important to you. How do you find that stuff out, where would you go to find that information?

Participant: Word of mouth.

One participant noted that some sources of provider information have their own interests that may depart from beneficiaries' interests. This participant emphasized that individual beneficiaries should be responsible for seeking out and sorting through information from various sources. The complicated choice should be made based on the beneficiary's own preferences and values. *To the extent that rural beneficiaries trust HCFA as a disinterested source, HCFA may be able to provide valued advice to help beneficiaries identify important factors and see important trade-offs.*

Beneficiary's Role in Sorting Through Information About Providers

If you do call, as you say, they will give you whoever is on their list. It's up to you to sort it out.

Participants generally reported relying on primary care providers as resources in selecting a specialist.

Primary Care Providers are Important Resources in Selecting a Specialist

My doctor was very nice, he recommends two and tells me to go talk to them and see which one you like.
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...I trusted him and I needed a specialist. It was someone that I didn't know at all, but I trusted him. ...You have to trust him. I trust him enough to go where he says.

Supplemental Insurance

A few participants seemed confused about the relations and functional distinctions between their coverage under Medicare and their supplemental insurance, but many participants seemed to understand the basic purpose of supplemental insurance and a few clearly understood the Medigap plan structure.

Some Confusion about Primary and Secondary Insurance

I keep getting this question every time from any time I use any medical [care]...[Is] Medicare your primary, or is it your supplemental? I didn't think there was a question there. I think maybe this is one thing that Medicare ought to tell us. It is automatically primary with whatever out you take picking up that which Medicare does not pay. That was my understanding...
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Some Clearly Understand Medigap Plans
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Moderator: Anyone else have comments on choosing a supplemental plan?

Participant: For choosing the supplemental, I would assume that you would look for the most coverage for the least amount of money.

Participant: All companies, A, B, C, D, E or F, are the same theoretically.

Hey, you're speaking of insurance company supplementals available, they are standardized. HMOs are different. Insurance companies A-J, these are standard, but I submit to you, having been in the business for 50 years, there's no simple way, unless you change the whole thing, to say which one is which.
--

Participants generally agreed that decisions about supplemental insurance were difficult for them to make. They mentioned two factors that contributed to the difficulty they had making choices. First, participants reported that experience is an important source of information about the kinds of coverage they'll need. Several participants noted that at the time they enrolled in Medicare, they had insufficient experience to anticipate their future needs. Second, many participants mentioned that they information materials that could help them make good choices arrived too late to be very helpful. Many beneficiaries indicated that materials delivered during the year before they enrolled for Medicare would

help them prepare for the decisions they would have to make. The choice of supplemental insurance was an area where these participants preferred proactive information.

Supplemental Insurance is a Difficult Choice

It's kind of hard to decide when you're still working or when you're ready to retire, it's kind of hard to do your homework, because you don't really know until you have a heart attack and go to the hospital, you don't know what you're going to need, what it's going to pay, what it's not going to pay. So it's hard to do your research and homework and make the right choices, because you really don't know.

Well, I think ... someone needs to tell you more about the coverage and what you're really getting and what you pay for. It's probably my fault that I didn't do enough research myself. I think you have to really do the research yourself.

Participant: And after you reach 65, then that's when all the information comes in. And you've already made your decision.

Participant: If you had it ahead of time, like a couple years ahead of time to plan your retirement—

Participant: Well, also, too, if you've had family members or yourself or spouse that has needed care, then you have something to think about, but if you're basically healthy, you can't imagine being—it's hard to imagine a heart attack or cancer. You don't know the questions yet.

Participant: ...if it said, read this before you sign up for your Medicare benefits if you qualify. I think people would start looking at it.

Participant: Just one thing is there's all kinds of people. They got different ideas. And I don't think you're going to come up with something that covers everything. Each person has got to—they got their own way of handling it. Some of them will read it. Some of them won't.

Participant: I think something has got to happen to draw attention to something in particular. And then they will concentrate on it.

Another factor that seemed to contribute to making supplemental insurance a difficult choice was the need to weigh and integrate information from several sources. As illustrated by the following quotations, participants highlighted the importance of individual preferences and judgment in pulling together information about supplemental insurance.

Beneficiaries' Role in Evaluating Information about Supplemental Insurance

I'm solicited, bombarded, constantly by various groups appealing to my changing to their better plan. There are a number of them.

I have a problem with that. Your various raters don't always agree... Therefore, it remains that this person, given this set of facts, comes to this conclusion. This one gives the identical set of facts and comes to a second conclusion. I know in insurance I've seen that too and so I am left with two people, supposedly both experts, both coming to two different conclusions. I am the one that has to decide. It's not easy.

Rural beneficiaries, like several other groups of beneficiaries, will benefit from early information about supplemental insurance. Some will need general information about the function of supplementary insurance under the Medicare program. Most will need detailed information about the Medigap plans. Of course this kind of information is already available to beneficiaries who know where to look. HCFA could provide a valuable service by centralizing information dissemination, distributing information at several time points. This information should be distributed early to enhance its usefulness, and it should be available either at several time points or across time to meet the needs of beneficiaries with different information strategies.

Staying Healthy

Rural participants mentioned their providers, the media and senior magazines as important sources of information about ways to stay healthy, and participants generally agreed that they get enough information about ways to stay healthy. Participants in the rural focus groups seemed less concerned about conflicting and changing information about ways to stay healthy compared with participants in focus groups for the general beneficiary population.

Providers and the Media are Important Sources of Information on Staying Healthy

Moderator: Okay. What about getting information about staying health? Where would you go to get information about that? Information about, you know, prevention.

Participant: Your doctor.

Participant: Your doctor.

Participant: Back to your family doctor.

Moderator: Okay. Family doctor. And are you happy with the information you're getting?

Participant: Yes.

Participant: I am.

Participant: I'd go to the doctor.

Participant: Well, there are magazines like Prevention and others of that type.

Participant: They have classes, too.

Participant: Oh yes, you go to the grocery store and there's information on fat and calories. They are talking about it all the time on TV and in the papers.

Participant: Prevention Magazine is a very good source. There's a lot of information on various subjects for your health, exercising and so forth.

General Agreement There is Enough Information

Moderator: So there are all these different sources of information about staying healthy. Do you feel that you get enough information?

Participant: More than enough...

Participant: I get saturated.

There's more than enough.

There is a mountain of information available. Good information.

A few participants identified medication as a topic where they appreciate the information available to them. These participants mentioned providers who help them clean out their medicine cabinets and information about drug interactions available from pharmacies as valued resources.

Information about Medication is Available and Appreciated

Well...a doctor will ask the patient to bring in every medication they're... often you'll find he'll say, "You shouldn't be taking these two at the same time. Or throw that out. Or this is too strong."

Participant: There was some things on this... A local druggist that we deal with has a computer with all the medicine that you take in it. And if the doctor gives you a new prescription, he'll tell you if it conflicts with anything you've been taking or have taken. And it's a protection. ...

Participant: Yeah. Our drug store gives us a yearly update of what we're on and all this stuff. It's really good.

Other Information

Rural focus group participants echoed some general concerns about Medicare fraud and the future of the Medicare program that were also raised in focus groups for the general beneficiary population. *Like other beneficiary groups, rural beneficiaries are interested in information about how to detect and report suspected fraud.*

Concerns about Fraud and Abuse

That is my concern....This over billing ...may ...strangle itself. We may have to do without. Our costs individually will have be increased because the covered people just can't afford this.

Yes, I think there should be a general mailing or some sort of communication... They should be alerted to report to some central body that they suspect there is fraud.... I don't know if we have the facility to get to Medicare to tell them how we, as recipients of their services, think that they are being treated. They are being double billed, all these other things.

Participant: Well ... Sometimes they charge you for a procedure you didn't get.

Participant: And they don't itemize it.

Participant: Right. They don't itemize it. And you don't know really...

Concern about the Future of Medicare

I was just going to say that last night on the news they was talking about ... cutting the Medicare growth. And they said ... that what they're talking about in Congress now, is they're going to cut the pay to the provider, which would be your doctor. And they said there was going to be a lot of doctors that was going to refuse to treat Medicare patients.

3.6 Major Findings for 64-Year-Olds About to Enroll in Medicare

Participants about to enroll in Medicare described some information-seeking strategies similar to the proactive and passive strategies described by general population beneficiaries. Participants about to enroll in Medicare described additional information-seeking strategies that seemed especially suited to their situations. For example, several participants reported that they learned about the Medicare program and how it is structured through the experiences of spouses and other family members already enrolled in Medicare.

Information-Seeking Strategies

Proactive Strategies

Moderator: How about the rest of you. Have you been looking for Medicare information?

Participant: I got some down at the social security office. I also went to AARP because every place that you go the information is slanted. I'm now in the process of trying to get individual information from individual insurance companies.

Moderator: How about the rest of you, where are you in terms of supplementary insurance?
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Participant: Still getting information.

"I'm just learning. I don't really talk to anyone. I'm trying to see what the basic, just trying to get basic information on Medicare or other HMO's to see what is likely for what I need. It's individual. There's HMO and there's Medicare and supplement. It's just a matter of getting information."

I'll be 65 in November. I have the books on Medicare to try and figure what the options are. In fact last Wednesday I went to a seminar...
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"I'll be 65 in August. I'm just starting to research health insurance. Presently I have insurance with my company and I'm very happy with it. I realize at 65 I can't maintain that insurance so I have to look at Medicare or other options. I'm just at the beginning to look at it ... and it's very difficult to get specific information. There is information in the book. When you read a booklet, I find that there is always some question and I find that very difficult."
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Passive Strategies

“I would like them to send me information that tells me the best way, the best insurance to get that. I am pretty old and I don’t know all of things and I am not out there in the world where I get all of it. I would like for them to send the best way, the best insurance, the best way to go to get this insurance that I really need that is not going to cost me half of my pay that I get every month.”

“It would seem to me that the people—you paid this money into Medicare. They got your name. They got your date of birth. The same way as the IRS has got your name and your number.... And it would seem to me that maybe six months or so before an individual turns 65, that the agency that’s in charge would get that information and at least send a notice out to the individuals if they’re interested in getting a document. These documents that I saw were very comprehensive documents. They were good documents, but as the gentleman says, he didn’t even know that he was supposed to go three months before. It would seem to me that they should send out a document, at least a post card or something like that, if you want further information you can get it from such and such.

Learn Through Experiences of Spouse or Other Family

I asked my wife, because she gets it. And she’s eligible for my plan.... I was paying the deductible for her. And as soon as she became 65 ...by Medicare kicking in, Medicare became the primary plan. Blue Cross and Blue Shield became the secondary plan, thus eliminating the deductible. And this is the way I found it out... once I become eligible, I will no longer pay a deductible.

Some time ago I did for my father when ... I was helping him in his last years. And, yes, at that time, I guess as much as anything I was trying to understand what Medicare would do for him and what it wouldn’t do for him.

“... My husband is already on Medicare as of about two years ago. And so I’m familiar with it. I really haven’t looked for myself.”

I’ve been retired for 10 years. And I’ve had [insurance plan] during my career. And since I’ve retired I’ve been paying it. When my wife, who reached the age of 65 prior to me, when she goes to the doctor or to the hospital, my [insurance plan] picks up my plan B and pays it. She doesn’t have to pay anything. So I see no need to get anything else, because I’ll use the same plan...

I” will be 65 in November. I know a little about Medicare because my husband is some years older than I am and he’s been on Medicare.

One participant who seemed intimidated by Medicare’s complexities reported that she would probably work with a friend in seeking information about Medicare and using it to understand her options. Another spoke very clearly about individual-specific information preferences and difficulties developing information that will satisfy people with different strategies for gathering and assimilating it.

Collaborate with Friends to Gather and Synthesize Information

Participant: “Well, I’ve got to decide which—and that’s hard to do, which supplemental thing. Some day I’m going to go over to a friend of mine and discuss it with [her].”

Moderator: And she’s made the decision already for herself?

Participant: Oh, no. She’s younger, but between the two of us, I figure just talking about it I’ll be able to make up my mind.

Person-Specific Approaches and Preferences

“I think people either delve into it and get as much information as they can or you have the other end where people just look at it and don’t think about it.”

Participants talking about their approaches to finding information also spoke about their preferred sources of information. Several participants reported that seminars, classes and group meetings are good resources for them because they provide opportunities for sharing ideas and getting advice from many people at once. Many participants mentioned HCFA as a preferred resource because participants trust the government to provide unbiased information. Participants also mentioned their primary care providers as trusted sources of information.

Seminars and Group Meetings are Helpful

Going to seminars does help.

Even small groups, you can bounce it back and forth. What he has told us about HMO’s, now this to me is slightly enlightening.

Participant: ... the idea, to go up there and have a class, and you know, itemize what goes here, what goes there....

Participant: Examples. I think that’s very, very good.

HCFA is a Trusted Resource

I would like ... [HCFA] to send me information that tells me the best way, the best insurance to get that. I am pretty old and I don’t know all of things and I am not out there in the world where I get all of it. I would like for them to send the best way, the best insurance, the best way to go to get this insurance that I really need that is not going to cost me half of my pay that I get every month.

Participant: And most of these people you know that you cannot trust but I figure that my government, I better trust them or I am in bad shape.

Participant: Yeah. They’re not selling anything. They’re just telling you.

Primary Care Providers Are Also Trusted Resources

“....Does that include ... [my doctor’s] billing department? Because I was thinking of calling them and ask them how their insurance companies pay off.”

“It’s just so confusing when you get so much information form here, from there then you want to use the best judgement of choosing the right package for you. I trust my doctor you know he’s ok with my doctor so I am going to ask him..”

Individuals about to enroll in Medicare have identified some specialized information-seeking strategies. Other beneficiary groups may benefit from these strategies. A goal for the Synthesis Report will be to identify ways to build on strategies that work well for some situations to make them available to broader groups of beneficiaries.

Basic Program Information

Focus group participants about to enroll in Medicare were diverse in terms of what they already know about the Medicare program and the types of information they want or need most immediately. Some participants already had basic information about how the Medicare program is structured and how Medicare components work together to provide coverage for health services. These participants seemed to understand the different purposes of Medicare Part A and Part B and how supplemental insurance works to fill in additional coverage. These participants also seemed to understand that Medicare HMOs are set up differently from the Medigap supplementary plans.

Some Already Understand Medicare Structure and Program Components

Myself, I haven't gotten on Medicare yet. It will be in August. And I already got the information, Part A, Part B. And I would like to get some more information on the Part B, to see how much it's going to cost, because the supplemental, ... HMO and all the other ones... and all that, what it amounts to is \$100 more.

Also, Medicare, for example, will say, "This is not covered." If you're not careful, and you're billed for something that is not covered, and Medicare comes back and says, "This is not covered." that supplier can come back and say, "You owe me this." No, no. You get your letter from Medicare. Look at this. It says on there that you're liable for anything Medicare does not cover. If Medicare does not cover it, you owe it.

I think you keep on talking about HMOs and their regulations and I thought Medicare was different. You don't have to go by regulations. You just sick you go. You go to whatever doctor you want. You give them the Medicare and then they pay 2 cents on the dollar or whatever and you get your supplement and that picks up part of the difference and then you go into bankruptcy.

Yeah. And even if I do get Medicare, I know I'm going to have to get a supplement, too.

I'm as yet undecided as to where to go with it, whether to stay with my HMO, or to go Medicare with supplement.

No, but I have a Blue Cross/Blue Shield plan. And what I'm getting at is, when my Medicaid kicks in, my Blue Cross and Blue Shield become my, I guess, secondary plan. And you have to have one because Medicare would be the primary plan, is what I'm getting at.

While some participants had clear understandings about the Medicare program and how it is structured, at least as many seemed to lack basic information about how Medicare works and what it covers. These participants seemed confused about the roles of primary and secondary insurance and the relations between Medicare Part A and Part B. They seemed uncertain about the utility of supplementary insurance.

Basic Questions about Medicare Program and Its Components

So my question here is what do I have to do for Medicare?

The difference between ... the insurance companies that pay claims for Medicare versus your supplemental insurance company...?

I retired two years ago. Right now I still have coverage from my company. I will be 65 in October. I don't know the first thing about Medicare. Are you automatically enrolled? How do you go about it? I don't know the coverage.

Then you mentioned that they're primary and the other one... is a secondary. A thought comes in, what difference does it—I mean, I don't know. Is there an increased coverage?

Participant: It would appear to me..., like the Blue Cross and Blue Shield, upon ... age 65, they would notify you that they were terminating your Plan B, because you no longer would have to pay into it, after you're 65..... I'm not too sure, ...but if it is, then I'm sure that they will notify you.... I don't think they would continue to charge you for the Plan B...

Participant: That's the optional.

Participant: Is it optional?

But what I'm saying to you is that—what I'm saying is that once you pick up Medicare and your regular Blue Cross and Blue Shield will act as the Part B and you don't need that, right?

Now is Medicare always the primary?

The diverse levels of knowledge and comfort evident across participants about to enroll in Medicare suggests that effective information is accessible to some but not all individuals about to enroll in Medicare. These differences probably reflect combined effects of different information-seeking preferences, different background knowledge and experience with insurance, social networks with different levels of experience with medicare, and different preferences across information channels, formats, and media. Our focus groups were an effective means for identifying these factors. *Survey data collection with individuals about to enroll in Medicare will be an effective means for evaluating the effects of each of these factors on access to and satisfaction with informaiton about Medicare.*

A few participants seemed to need background information about insurance concepts and conventions. For example, one participant was not familiar with insurance deductibles.

Needs for Background Information about Insurance Concepts and Conventions
Participant 1: Does he have a deductible?
Participant 2: What do you mean, deductible?
Participant 1: Like when you go to the hospital, if you have a surgery, you have to pay.
Participant 2: I don't know.

Many participants commented on the apparent complexity of the Medicare program. They seemed intimidated by the program's complexity. Several participants noted that information about the program is also difficult to understand. *If perceptions of the program's complexity are influenced by the difficulty that individuals have understanding information about the program, then finding simpler and more effective ways to present program information will simultaneously make the program itself seem more accessible and customer oriented.*

Medicare Program Seems Complex
I think for a lot of people it's very confusing.... Just the whole concept of Medicare, health care, long term care, supplements. I think it's overwhelming to a lot of people.
It's just overwhelming. Some people don't even know the difference between Medicare and Medicaid.
Our system's the most complicated in the world.
"... But even more helpful would be for them to explain exactly how it works, because the people don't understand how it works. And then they get perturbed. For instance, such things as what's allowable and how much of the allowable will be paid. If they're going to cover 80%, you have to cover the other...[20%]."
We're reaching a time of our life where abilities, natural abilities are decreased. Why not make it less complicated?
Participant: One of the primary reasons that you do not get information from the doctor is because on your explanation of Medicare benefits when you get your bill and it explains it, the procedures done are never mentioned there, only a code. And if you know the code, then you know what they're talking about... what I'm telling you is, that they are governed by codes....
Participant: It may be advantageous to the government to have a billing where the patient can understand it.

Information about Medicare is Also Complicated

It's just so confusing when you get so much information from here, from there, then you want to use the best judgment of choosing the right package for you....

But the point I really want to make is, let me just tell you, we're all sitting here kind of confused about a lot of things. And let me just tell you it doesn't get better as we get older. It's going to get worse. ...It is most difficult to find two places that tell you the same thing. In fact, some of these forms they sent to my mother-in-law that she has to fill out, there's no way in the world that she could do that if my wife and I weren't there to help her.

Participants generally agreed that there is a role for HCFA in providing clear information for people about to enroll in Medicare. Participants thought of HCFA as a good resource for basic information about how Medicare works and for information comparing alternative health care plans and options. Several participants commented on the value of question-and-answer sessions conducted in face-to-face meetings.

Participants Identified Some Roles for HCFA in Providing Information

Moderator: So that might be a role for the government agency, is providing this general overview and helping you sort through, maybe, the sales claims....

Participant: Like a supplemental trade fair or something where all of them are represented that want to be represented, that want to give you the information, right....

Participant: Yeah. They're not selling anything. They're just telling you.

I would like to suggest,... perhaps if HCFA had seminars and invited those genuinely interested in them, to come and ask all kinds of questions. It would be very helpful, but even more helpful would be for them to explain exactly how it works, because the people don't understand how it works. And then they get perturbed. For instance, such things as what's allowable and how much of the allowable will be paid. If they're going to cover 80%, you have to cover the other...

Moderator: ...You mentioned in-person meetings. And I'm wondering what the rest of you think about a meeting in-person. Would that be helpful?

Participant: With whom? With the HMOs? I don't think they give you accurate information.

Participant: Well, I think with your federal—...HCFA or whatever they are. Yes. I think, you know, an informational meeting where they could point out what are these supplemental plans, and what has the government said that this is what the supplemental plan has to consist of.

We've described several general information needs identified by participants about to enroll in Medicare. Participants also reported more specific information needs. For example, participants had questions about enrolling in Medicare. Participants asked whether enrollment is automatic and whether enrollment is voluntary. Participants who planned to continue working after they turned 65 were confused about what they should do and about how Medicare fit with their employer-provided insurance. Several participants asked about waiting periods and about the three-month enrollment "window" they had heard about. Some wondered whether they would be able to enroll in Medicare at all if they missed the three-month window.

Questions about Enrollment Processes

Well, I'm approaching 65, as a matter of fact, next week. And I had read that you had to apply for Medicare, 90 days, at least 90 days prior to your 65th birthday. And somehow or another that slipped And somewhat panic stricken I called to see just what was going on. And I wasn't aware... that really I didn't have to even worry about, because I'm going to continue working. So I don't have to even worry about it. And that's why I called them to find out what's going on. Was I eligible? Did I have to apply? Had I missed my window?... There was nothing in anything I read that stipulated that you did not have to take Medicare if you were going to continue to work.

Participant: When you need that Medicare, when would you get it?

Participant: Almost immediately. There is no waiting period at that point in time. If I'm terminated from my—

Participant: So five years from now, if you want it, you just call them up, ask for it and it's yours.

Participant: Well, you go through certain steps, I'm sure. You don't have to worry about a waiting period.

Participant: I didn't know that.

I figured that when you filed for social security that some of this became rather automatic, because I did file for social security beginning of October, beginning of next year. But I don't remember filing anything specifically for Medicare, but I have received my card.

I'm still working so I have my coverage through work. I hope to continue to work so I don't know if at 65 I'll be forced to go on Medicare. I think you have a choice now unless the company says no. I've really not looked into it too much. The one question that I did ask, no one seems to have that answer, do you have to go on Medicare if you have other insurance?

One other thing I would like to ask. Suppose Medicare time comes around and you don't enroll in Medicare. I heard something about you have three months to enroll and if you don't you can't get in it anymore? I would like to know about that. What's my options? Can I say well I am going to try an HMO and if it doesn't work out and now I want to go into Medicare.

Participants also had specific questions about Medicare assignment. Participants asked how they should go about finding providers who accept Medicare patients and Medicare assignment. Participants were confused about the differences between providers who accept Medicare patients and providers who accept assignment. Participants suggested that HCFA develop conventions that would make it easy to find out whether providers accept assignment, including signs posted in providers' offices and regional directories. Some participants were not sure how to work with providers who accept assignment. They had questions about the payments they should expect to make and how Medicare would handle reimbursement.

Questions about Medicare Assignment
<p>Is there a difference between a participating doctor and a doctor who doesn't accept assignments?</p> <p>Participant: Is there such a thing as them not accepting a patient or do they not accept assignments?</p> <p>Participant: I don't think they all accept—</p> <p>Participant: I would think they would all accept Medicare patients but—</p> <p>Participant: I was told that they would accept no new Medicare patients. If they had been a patient of the doctor before they were on Medicare, he would continue to accept them.</p> <p>Participant: I guess you have to call each individual doctor right now.</p> <p>Participant: They could have a sign...</p> <p>Participant: That's right. That says we do not accept Medicare—</p> <p>Participant: Right there on the window. It should be posted.</p> <p>Participant: There should be a directory mailed out for all of the doctors in the regional area that accept Medicare and those that don't</p> <p>Participant: I don't see why they can't make a directory of those who accept Medicare....</p> <p>Participant: A lot of the doctors would be kind of an either/or. Like this one I'm talking about. He would accept me while I'm on Medicare, but he won't accept a new client. So there's going to be a long list of either/or.</p> <p>My wife... went to a dermatologist the other day and he told her that he didn't accept Medicare. She would have to pay him and Medicare would send her a check. I guess he would send a bill to them and Medicare would send her a check, and she could pay him either then or later. But I didn't fully understand it because I didn't get a chance to talk with him.</p>

Coverage was another topic about which participants had questions. Some asked very general questions about what Medicare would cover and whether their providers would accept Medicare insurance. Others had questions about specific services provided and coverage limits.

Questions about Coverage

Moderator: ... what information do you need next.

Participant: Coverage....

Participant: For most people what is important is where you can go for doctors. Can I take the same doctor, that type of thing? Will my doctor accept this? Rules and regulations, hospitals....

Participant: Who to call....

Participant: Cost....

Participant: One thing what they will pay?

Participant: Say how many times you could go back or do you have to wait for a month or can you go back twice and then have the doctor refer you to somebody else immediately. Not have to having to call a primary, have to call a specialist and then the specialist says well you can't come for a month.

Participant: I didn't think Medicare worked that way. I though you could go to your doctor whenever you wanted to and you could go to a specialist on your own whenever you wanted to in Medicare.

Participant: I think Medicare ought to pay for hearing tests and glasses....

Participant: There are so many things that, like prescriptions, you know...

One participant was particularly articulate about the general confusion over Medicare options that seemed to characterize at least some participants in all four focus groups with individuals about to enroll in Medicare.

General Confusion

I haven't decided yet what I will do or if I am going to take; I am confused all the time.... My main question would be which ones are the alternatives. This is a priority that we are facing and are about to face in the future that we're going to be on a fixed income. Medicare is quite expensive, the deductions are high. So my plan is to join some kind of HMO or whatever.

Individuals about to enroll in Medicare need diverse kinds of specific information, including information about the enrollment process, information about how providers work with Medicare, and about coverage under alternative Medicare options. Again, this information should be available in a variety of formats and through diverse channels and media to ensure they reach these individuals who have different information-seeking strategies and different information preferences.

Choosing a Provider

Participants mentioned several resources they use when they need to find a provider, including friends, family, other providers and information provided by insurance plans and provider referral resources.

Resources for Finding a Provider

Moderator: So it's first ask about where you get information about choosing a doctor? Where do people go to get information about choosing a doctor?

Participant: Friends....

Participant: When I need a specialist, I go to my family—

Participant: Usually your doctor recommends someone....

Participant: [My insurance plan] ...every year sends out a booklet of all the practicing doctors under the plan. And I think that's very helpful. And they have them broken down into different categories, as to what type of medicine they specialize in, which is very helpful.

... but as far as looking for a doctor, isn't there some local places everywhere where you call and they give you list of doctors who specialize, with certain specialties, you can call and get that number?

Participants also mentioned some selection criteria that are important to them, including whether providers accept Medicare patients, provider communication skills and availability, and providers' past performance, including information on malpractice.

Provider Selection Criteria

Accept Medicare Patients

A lot of doctors will not take Medicare.

Well, I asked in my doctors office the last time I was there, and they said as long as you were a patient before you came on Medicare he would continue, but not new patients

Participant: I guess you have to call each individual doctor right now.

Participant: They could have a sign...

Participant: That's right. That says we do not accept Medicare—

Participant: Right there on the window. It should be posted.

Participant: There should be a directory mailed out for all of the doctors in the regional area that accept Medicare and those that don't.

Communication Skills and Availability

.... When I go to a doctor and I sit down and talk to him, I tell him if you got time for me then I would like for you to be my doctor but if you don't have time to sit down because a lot of doctors take you into that room, they wait on you, they push you right out the door. I want to be sit down in his office and him talk to me ... tell me something that convince me that he is doing something for me.

Past Performance

Well my husband is about to go in for his open heart surgery again I asked the doctor what his percentage of fatalities was.... I heard that a doctor is suppose to tell you and they did... but he actually told me what the hospital's percentage was which is important.

Participant: I would like to know how many years he's been practicing and what schools he graduated from. And if he has any malpractice cases filed against him.

Participant: Do you really want to know all that?

Participant: Yes I do.

Several participants about to enroll in Medicare reported that they had too little information about providers. Some participants thought there might be a role for HCFA in providing information and making recommendations about providers, but other participants were wary of HCFA involvement, particularly in making recommendations. These participants noted that HCFA recommendation would involve politics and they would be concerned that beneficiaries' interests would not be a primary consideration

Shortage of Provider Information and Potential Role for HCFA

Moderator: ...Do you feel like you have enough information to help you choose a doctor when it comes time to do that?

Participant: Definitely not.

Participant: No.

Participant: I believe if the government had Medicare, a list of doctors that really qualify to take care of your needs. You know if they had that list it would be a great help to the people that are trying to come into this.

Participant: It sounds political.

Participant: I tried when I spoke to the hospital...and spoke to other people but where do you find it?.... So there really wasn't anybody you know ...But it's really very difficult to find that out and I think that's important...

Medicare HMOs

In general, participants about to enroll in Medicare seemed to be familiar with HMOs, and a few participants clearly understood how HMOs work under Medicare.

Some Understood How Medicare HMOs Operate

Participant: They are a Medicare contractor. They take your forty-some dollars or whatever it is, from the government. You don't pay anything else. And they give you all the care you need....

Participant: They also have their own doctors, right? They don't—

Participant: Well, they also have contract physicians. Everybody has—

Participant: It's more or less like HMO.... They call them PPOs.

The moderator's guide for groups with individuals about to enroll in Medicare differed from the guides used in most other groups by explicitly asking participants about the kinds of contact they have had with Medicare HMOs, what they think about the information they have received from Medicare HMOs, and what information about Medicare HMOs they would like to receive from HCFA. Participants reported having few questions about Medicare HMOs, but they also mentioned several concerns, including quality of care, restricted provider choice, continuity of care and convenience.

Concerns about Medicare HMOs

Quality of Care

And I feel like most of the doctors that belong to HMO are second rate doctors.

Restricted Choice

But what I'm saying is, I don't want to go to a HMO... I want to have full pick of doctors. So I want to have a policy that gives me that freedom.

But the problem is, you don't have a great deal of choice... by your personal physician within the HMO. So even though they have, you know, this [list] of persons... you could go to. They really control to whom you will go.

But with an HMO you don't have—you have some choices, but it's not—and it might not be the one you want.

Continuity of Care

...I don't love HMO's because I always think the doctor is going to drop out once I get settled in and I'm not so quick to change doctors.

Convenience

And they might be way across town where you need to get to it too.

The reason that I am concerned about the HMO is because I have to find one where I have my doctors. And if I have one doctor in one and one doctor in the other that's no good because I have to very serious, incurable illnesses and I need my specialists. And I can't sit around and wait six months. So that's the problem with the HMO.

Supplemental Insurance

There were broad differences in what participants already knew about supplemental insurance. Some participants clearly understood what supplemental insurance provides and how the Medigap plans are structured. At the same time, there were misunderstandings and gaps in participant knowledge. Several participants seemed confused about supplemental insurance. The latter participants seemed to need basic information about the purposes of supplemental insurance and how supplemental insurance works.

Some Understand How Supplemental Insurance is Set Up

My question is, that I pay so much per year in premiums for my health insurance at the present time. And that's standard option with [insurance company]. And when I reach Medicare stage, I know that they pick up as primary. And I have the option of buying a Medigap policy ... And I do know that they charge \$46 a month for Part B. And I know that you don't have to take Part B. And I was just wondering if I [will] still continue to pay my money ...while I have some kind of supplemental policy...

I contacted a few insurance companies and asked them to tell me what Medigap plans they provided and what their rates were. But the plans were all identical, but the rates are quite different from one insurance company to another.

I'm retiring the government, and concerned about the transition, once you get from what you're paying regular health insurance right now to what happens with Medicare. I know that they become the primary and that ... whoever I have, become the secondary.

...And that's very key. A lot of government employees don't know that, ...See when you're in the military—when you're in the federal government, there's no need to have an HMO, because ... you can go to military hospitals. But now that you're getting ready to retire, you need to pick up an insurance, because when you get 65, CHAMPUS is no longer valid.... And what you get is Medicare. And you have to have another policy help you along with Medicare. Now, people lose, and no one makes that clear to them, but I just went through it last month. That's how I happen to know this. But that's very important.

There Are Misunderstandings and Gaps in Knowledge

...I picked up some documents there about Medicare.... And they explained about the 12 or so different types of gap plans, but they don't really [go] into premiums. It was very well documented, but it still didn't answer my questions 100 percent, as far as what happens from the standpoint of my health insurance. I kind of guess right now that if I still pay my premium for my government health insurance, that I don't have to pay the \$40 a month for the part B supplemental with Medicare. And I'm not sure how all that plays out....But this is a year after reading—even after reading these documents, and they were very, very substantial documents—

...I don't know. I was told supplemental insurance would be needed. I never heard of Medigap.

Some Need Very Basic Information About Supplemental Insurance

What exactly is Medigap?

Participant: Did you get confused with all the categories, A, B, C to J. Who is going to sit down and figure that mess out.

Moderator: Did you find it confusing?

Participant: Yes, we did...

This is kind of confusing, because, you know, you have insurance before you get to 65. And that same insurance that you have before you get to 65 could be a Medigap policy once you turn 65.

I would like to know about different things they said. You mean to tell me that there is something that Medicare will pay and you get another something after the \$42 you can, there is something else you pay and get more? Is that what you just said.

That I don't know. I was told supplemental insurance would be needed. I never heard of Medigap.

Well I think that Medicare should send you a book. There must be doctors who accept whatever ... [Medicare] gives you without you having to get a supplement.

We have already noted that some beneficiaries about to enroll in Medicare do not have access to information describing the program, how it is structured, and how the components work together. We recommend that HCFA provide this kind of information early, in several formats, and through a variety of channels and media. This should include layered information about supplemental insurance.

Participants identified some criteria for selecting a supplementary insurance plan, including coverage for prescription medication, provider choice, convenience in paying for services, and cost.

Important Features of Supplementary Insurance Plans
<p>Coverage</p> <p>I have a great plan....They had the supplemental Medicare insurance policy which will pay prescriptions, 85 percent, whatever Medicare doesn't pay for they will pay 85 percent.</p> <p>... but we're not going to go for the biggest coverage because of Medicare. Hopefully, the supplemental will pay for what Medicare doesn't pay and so we're not going for the biggest coverage.</p> <p>Provider Choice</p> <p>I was listening to the television and they were talking about one particular company and I seemed to like it because you can go to any doctor you choose. And that's the kind I am looking for. And I am looking for something where the social security will take out for the supplement and everything if there is a possible company like. Is there a company that will pay all of your needs so you don't have to pay the second time for a supplement just the whole thing and just take care of one thing.</p> <p>Convenience</p> <p>Yes I would like something whereby everything is taken out. I guess it has to go through social security.</p> <p>Cost</p> <p>Have you noticed that the prices are from \$80 per month to \$130 per month. You really have to go over these groups.</p> <p>But I think the question that follows is, whether or not when we're no longer working we're going to be able to afford it.</p>

Several participants using proactive information-seeking strategies to prepare to make a decision about supplemental insurance. A few seemed to have no strategy for preparing to make decisions about supplemental insurance.

Supplemental Insurance Decision Strategies

Active Information Seeking

Moderator: How about the rest of you, where are you in terms of supplementary insurance?

Participant: Still getting information.

I'm just learning. I don't really talk to anyone. I'm trying to see what the basic, just trying to get basic information on Medicare or other HMO's to see what is likely for what I need. It's individual. There's HMO and there's Medicare and supplement. It's just a matter of getting information.

We haven't decided yet but we are getting prices. We know we need one. We've gotten some prices...

...So, we're just pulling from a lot of insurance companies.

...About two years ago, I was in the [insurance company] headquarters... and I picked up some documents there about Medicare, but at that time I wasn't really eligible. I was a couple of years away, so I just put them back on a bookshelf. And about two weeks ago I picked them up and started to read those documents.

I've looked at two Blue Cross plans. I've looked at AARP. I've looked at one through my automobile insurance company, USAA. And coverages are identical, and the least expensive is USAA. So that's who I'm going to go with.

Well, I've called a lot of places and I'm just collecting it all together now.

Participant: I found out from the insurance company that I have now. I called them to make sure that I could continue with them after I had Medicare, and what would the changes be, only to find out that they don't work with Medicare. And I'll have to get a new one. They didn't recommend anybody. They just—

Moderator: So they were not helpful there.

Participant: Not in that respect. They were helpful in the fact that I then knew that I was going to have to have coverage, additional coverage, but no, not in who to get.

No Decision Strategy

Moderator: Do you have any plans?

Participant: Yes, I do.

Moderator: What?

Participant: ...when I said it was an arm of the social security, I thought that that's what it was when I remember reading about it in the document, but I have to find—I have to get a number to call...

Participants mentioned some resources that have been useful to them in exploring their supplemental insurance options. *Several participants noted that seminars and group meetings are particularly useful for gathering information. They suggested that HCFA could help them considerably by sponsoring seminars and question-and-answer sessions focusing on supplemental insurance.*

Seminars Are Useful Forums

Participant: ...[They] have groups where they invite you to come to... where they tell you about these programs. I haven't been to any, but I have had invitations from a couple of insurance companies that wanted to sell me Medigap insurance.

Participant: I've gone to some of those, and they make it—they really paint a rosy picture....

Moderator: ...You mentioned in-person meetings. And I'm wondering what the rest of you think about a meeting in-person. Would that be helpful?

Participant: With whom? With the HMOs? I don't think they give you accurate information.

Participant: Well, I think with your federal—...HCFA or whatever they area. Yes. I think, you know, an informational meeting where they could point out what are these supplemental plans, and what has the government said that this is what the supplemental plan has to consist of.

Staying Healthy

Participants about to enroll in Medicare generally agreed that they get enough information on ways to stay healthy. They identified a variety of resources for information about staying healthy. The resources included their primary care providers, their HMOs, other medical specialists, magazines and newsletters for seniors, and health fairs. They reported that similar resources are also useful for information about chronic conditions.

Sources of Information

Staying Healthy

Moderator: In general, where do you go to get that kind of information?

Participant: HMO's are good at that.... They're preventive health there. ...

Participant: Physician....Your doctor.

Well, you know now. Some of these doctors will refer you to nutritionist, for example, or an occupational therapist. These kinds of specialty areas you get referred to.... You'd be amazed at what these nutritionists can do for you. They help you with your diet. They help you do a whole lot of things, you would feel a lot better too.

It's one thing to say where do you get information about things, but when we're talking about health, the main thing, the bottom line is go to the doctor period. Instead of looking for information about all of these things, go to the doctor and get a complete physical...

Participant: I get mine from HMO....

Participant: I don't think there's any shortage of information.

Moderator: How about preventive medical care? Things like regular check-ups and flu shots and mammography for woman and so on?...

Participant: My doctor always inform me.

Participant: My doctor sends me a card telling me that it's time for this and time for that.

Moderator: Now what about getting back to information about staying healthy, any other sources?

Participant: Newsletters.

Participant: The Heart Association....

Participant: There's a lot of them out there.

I receive a Wellness magazine once a month. And the Wellness magazine tells you what foods to eat to stay healthy and exercises and I read all that.

Every year they have a health fair and they take your blood pressure and your cholesterol. And they give you tons of information on foods, exercise, that type of thing. So these health fairs once a year are very good.

Chronic Conditions

Moderator: Do you feel like you get the information you need for these kinds of chronic conditions?

Participant: Well the best thing to do is to get in touch with a national organization. They have newsletters every month for your particular disease and they keep you updated on what's going and the medications, experiments and so forth so you really should be knowledgeable about what's wrong with you.

Well I could think most of these people, I've heard them allude to it, get these magazines, Maturity, Prevention, things that come in the mail that I don't even know where they come from. These senior citizen things which I assume comes because of my husband being on Medicare. And they give you a wealth of information about everything.

A few participants mentioned difficulties interpreting conflicting or changing information about ways to stay healthy. Difficulties with conflicting information seemed less important to participants about to enroll in Medicare than they were for participants from the general population of beneficiaries. However, one participant suggested that a comprehensive telephone helpline could be useful for individuals interested in more information or clearer information to help them access and understand information about their health

Conflicting Information about Ways to Stay Healthy
Participant: That's contradictory to hear one person say one thing and another say something else....
Participant: A lot of contradictory nutritional information.
Comprehensive Helpline Could Be Useful
You know it might be helpful... some comprehensive helpline where people could call into when they had questions.

Other Information

Several participants reported that they are concerned about the costs they'll have to pay under Medicare and about how they will budget for the costs.

Concerns about Medicare Costs
I say for this subject that we are touching, cost, cost, cost. In my opinion that is the most important thing I have as far as Medicare is concerned.
As far as Medicare is concerned, right now, when I turn 65, the only thing that I know is that I'm going to have to come up with \$40 more a month out of my pocket that I didn't have to do before.
That's my main concern but not only that I'm going to have to get supplements. That's going to cost me more. On top of all of that, while we are paying for medical care, it's now going to be deducted from my taxes, what is it one, two percent, in health care to deduct it from your taxes. So there is another expense.
Wait until you see the Medicare bills. The way it goes is if a doctor charges \$37 per visit and you have a supplement. The next thing you see will be a memo from your insurance company that the doctor charged \$37 and Medicare approved \$29, \$7 was sent to the insurance company, they are paying 85% of that and you owe \$4.20. If the doctor says \$100 then they will pay 80 percent of that.

One participant indicated that they'd like to receive information from HCFA that reviews and gives advice about the best Medicare options. It was not clear whether this participant believed that advice about options should be tailored to individuals' needs. It would be important to consider how to present this kind of information, since at least some participants about to enroll in Medicare seemed interested in information that makes Medicare options seem simpler and easier to understand.

Role for HCFA Identifying "Best" Options
I would like them to send me information that tells me the best way, the best insurance to get that. I am pretty old and I don't know all of things and I am not out there in the world where I get all of it. I would like for them to send the best way, the best insurance, the best way to go to get this insurance that I really need that is not going to cost me half of my pay that I get every month.

4. SOURCES OF INFORMATION

This section describes beneficiaries' comments about and attitudes toward potential information resources. Our analyses draw on two sources of information: Participants' descriptions of actual information-seeking experiences and results from card-sorting exercises that participants used to rank alternative sources of information according to the amount of information they had received from the source and on how much they trusted the source to give them accurate, complete information about Medicare. The general population focus group report describes the card sort exercises in more detail.

The focus group participants are not a statistically representative sample of either the Medicare population as a whole or of the subpopulations of interest, so any quantitative analysis of the results cannot be generalized. Quantitative rankings do provide a summary of focus group participants' attitudes toward the eight information sources ranked. Exhibit 4-1 shows the mean, median, and modal rankings for the eight sources, separately, for the amount of information received and for trust. Exhibit 4-1 presents results for the general population and for each of the beneficiary subpopulations discussed in this report. In all cases, lower numbers reflect better rankings. For example, the source assigned a ranking of 1 for amount of information was first in terms of amount of information, and the source assigned a ranking of 1 for trust was first in trustworthiness. Likewise, a source assigned a ranking of 8 for amount of information was last in terms of amount of information, and a source assigned a ranking of 8 for trust was last in trustworthiness.

We will discuss results from Exhibit 4-1 in the following sections, focusing on a single beneficiary subpopulation at a time, and covering reactions to each source in turn. In this introductory section, we will describe some of the criteria participants said they used to make these rankings. We will also describe group differences.

In the general population report, we identified the following four criteria that seemed important to participants as they ranked information sources:

- Knowledge about Medicare—both the amount and accuracy of information;
- Timeliness of information—up-to-date information available when it is needed;
- Clarity of information—making a complex program simple; and
- Strength and length of beneficiary's relationship with the source.

Exhibit 4-1

**Mean, Median, and Mode Rankings for Amount of Information Received About Medicare and Trust
Based on Focus Group Card-Sort Exercises, for the General Population and Subpopulation**

Amount of Information	General Population			African-Americans			Hispanic (English Speaking)			Dually Eligible			Rural Residents	
	Mean	Median	Mode	Mean	Median	Mode	Mean	Median	Mode	Mean	Median	Mode	Mean	Median
Family and friends	4.42	5	1	4.59	4	8	6.07	6	7	5.00	5	8	6.26	6
Medicare contractors	3.55	3	2	4.00	4	4	3.38	3	1	4.14	4	1	2.82	2
Doctors, nurses, clinics	4.10	4	3	4.17	4	2	4.63	4	3	3.40	3	1	3.15	3
Radio, TV, newspapers	5.22	5	8	4.83	4	3	3.87	4	1,4,7	4.44	4	3	5.59	5
HCFA	4.98	5	7	3.97	4	3,4	3.07	2	2	5.21	6	7,8	3.24	3
Supplemental insurance	3.92	4	3	4.70	5	7	2.53	2	2	4.19	4	5	4.21	3
People in the community	5.69	6	8	4.83	5	3,5	6.24	6	8	4.67	4	3,4	6.24	7
AARP and other groups	3.60	4	1	3.94	4	1	5.31	5	8	3.75	3	1	3.83	3

Trust of Sources	General Population			African-Americans			Hispanic (English Speaking)			Dually Eligible			Rural Residents	
	Mean	Median	Mode	Mean	Median	Mode	Mean	Median	Mode	Mean	Median	Mode	Mean	Median
Family and friends	4.97	6	8	4.56	5	5	6.27	7	7	4.83	6	8	5.55	6
Medicare contractors	3.71	3	1,2	4.58	4	2,4,8	3.71	3	2,5	4.50	5	5,7	2.88	3
Doctors, nurses, clinics	3.79	3	3	4.00	4	1,2,6	3.19	3	1,3,6	3.17	3	2	3.26	3
Radio, TV, newspapers	6.32	6	8	6.25	7	8	4.77	4	4,8	5.32	6	4	6.00	6
HCFA	4.09	4	1	3.14	3	1	1.86	1	1	4.79	5	8	3.25	2
Supplemental insurance	3.50	3	2	5.28	5	8	3.00	3	2,3	3.79	3	3	4.48	4
People in the community	5.62	6	7	5.04	5	7	6.64	6	8	4.71	5	3	6.00	6
AARP and other groups	3.65	3	1	2.73	2	1	4.87	5	2,4,5,7	3.86	4	4	4.23	4

These criteria seem to hold up as important for most of the beneficiary subgroups covered by this report. However, there were some differences in criteria across the beneficiary subpopulations. For example, for Spanish-speaking beneficiaries, an over-riding criterion was whether the source provided information in Spanish. Since many of the Spanish-speaking beneficiaries could not read in English or Spanish, another important criterion was whether the source provides information in non-printed form. Thus, mass media were more important information sources for beneficiaries with low reading skills than for beneficiaries with high reading skills. This was particularly true in areas where Spanish radio and television stations are available. Also, community resources and family and friends were more significant sources for these beneficiaries.

Some rural beneficiaries added privacy concerns to their criteria for ranking information sources. They valued “official” sources such as HCFA, Medicare carriers, and medical providers. They avoided sources with whom they chose not to share the details of their own health care and health insurance coverage.

Dually eligible beneficiaries were not always clear about the differences between Medicare and Medicaid. They preferred information sources that are knowledgeable about both programs. Dually eligible beneficiaries also seemed more likely than most other Medicare beneficiaries to view themselves in an adversarial relationship with “official” sources such as HCFA and Medicare carriers. Thus, an additional criterion for ranking information sources seemed to be whether the resource is separate from the sources responsible for determining program eligibility and setting benefit levels. Medical providers and AARP seemed to meet this criterion.

The figures in Exhibit 4-1 allow a variety of comparisons within and across beneficiary subpopulations. The discussions in the following sections describe the relative rankings of the eight sources separately, for each beneficiary subpopulations.

In the remainder of this introductory section, we will make some general observations about how the rankings compared across the beneficiary subpopulations. To do this, one set of statistics we will use is the range of the mean and median rankings. The range is the difference between the highest and lowest ranking, and it is one measure of dispersion. For the general population groups, the range of mean rankings for amount of information was 5.69 (“lowest”) minus 3.55 (“highest”), or 2.14. Similarly, the median range was 6 minus 3, or 3. For the trust rankings, the mean range was 2.82, and the median range was again 3. The wider the range between highest and lowest scores, the more uniform the rankings were across participants within a subgroup. The widest possible range is 7, which would mean unanimity on the highest and lowest scores. The narrowest possible range is 0, which would mean no agreement at all on the rankings. The ranges are important in interpreting the results; larger ranges imply more agreement

across participants within a beneficiary subgroup and hence more strength of opinion or uniformity across participants from a specific beneficiary subpopulation.

African-Americans had the smallest mean (0.89) and median (1) ranges for the rankings on amount of information, followed by the dually eligible beneficiaries (1.60 mean range, 3 median range). For these two groups of beneficiaries, there was less agreement about important sources than there was for other groups of beneficiaries. One possible reason for the lack of agreement within these beneficiary groups is that they received less information than beneficiaries in other subpopulations. This hypothesis was consistent with group discussions. The greatest agreement on amount of information came in the two English-speaking Hispanic groups (mean range 3.71, median range 4), perhaps because there were only two groups and they were in the same city. There was also strong agreement among the rural beneficiary groups (mean range 3.44, median range 4). For rural participants, the distinction between sources with whom they share personal health information and sources with whom they would not share personal information seemed quite strong.

In general, the mean ranges for trust were larger than those for amount of information. This was true for all study populations except for rural beneficiaries. For African-Americans, the difference in ranges for trust and amount of information was striking—3.52 vs. 0.89 for mean range and 5 vs. 1 for median range. Dually eligible beneficiaries had a narrow range for trust (2.15 mean, 3 median) and for amount of information. This indicates that findings for dually eligible beneficiaries are particularly tenuous.

Comparisons between the rankings for amount of information and for trust within beneficiary subgroups provides additional insight. Many beneficiaries gave identical rankings for trust and for amount of information. To the extent that the rankings are different, they suggest gaps between where information is coming from and where it should be coming from (from the beneficiary's perspective). Our gap analyses subsections follow. This section will conclude with a brief discussion of the gaps by subgroup, focusing on gaps between mean rankings wider than 1.

Results from gap analyses indicate that African-American beneficiaries are getting too much information from the mass media and too little from AARP and other senior citizens' groups. English-speaking Hispanics are not getting enough information from medical providers and from HCFA. Individuals about to enroll in Medicare are getting too much information from family and friends and from the mass media. Those about to enroll in Medicare are getting too little information from HCFA.

Neither dually eligible nor rural beneficiaries had noticeable gaps between amount of information rankings and trust rankings. For dually eligible beneficiaries, the small gap may be related to the narrow mean and median ranges; there is less agreement about sources among dually eligible beneficiaries, hence an equivocal view of sources they would like to receive more information from. For rural beneficiaries, the small gap may be related to the importance they place on personal privacy. Rural beneficiaries may seek out information from trusted sources more than other beneficiaries do.

4.1 Major Findings for General Population Beneficiaries

Family and Friends

In the general population, the rankings for “family and friends” were bimodal. Participants ranked family and friends either very high or very low. Few participants were neutral about family and friends as sources of information. Participants who had older spouses, older friends and family members, or friends and family members in medical professions reported that they used their friends and family as frequent sources and that they trusted the information. People who reported relying on family and friends as frequent sources of information were more likely to be reactive rather than proactive about seeking information, and they also seemed intimidated by information from “official” sources. People who said they do not get Medicare information from family and friends generally agreed that their family and friends mean well, but they do not have the required experience with or knowledge of the Medicare program. Family and friends were most often cited in discussions as sources of information about supplemental insurance and choosing a doctor, as well as for general information about Medicare.

Insurance Companies that Pay Claims for Medicare

Among participants from the general beneficiary population, there was considerable confusion about the difference between Medicare contractors, HCFA, and supplemental insurance companies. Many participants did not make clear distinctions as they ranked the information sources. Participants ranked Medicare contractors high for the amount of information provided but low for trustworthiness. We observed a range of reactions to Medicare contractors as information resources, probably in part because beneficiaries’ experiences with contractors differed across the focus group sites. General population participants who said they do not trust their Medicare contractors as sources of accurate information cited delays, mistakes, lack of follow-through and general distrust as reasons.

Doctors, Nurses, or Clinics

General population participants reported that they rely on and trust information from doctors who are willing to take the time to talk with them. Participants' relationships with their providers were related to the likelihood they would rely on information from their doctors. Participants who had good relationships with their doctors trusted the information they got from them; participants who had weaker relationships with their providers were less trusting of information they got from their providers and said they relied more heavily on other sources. Participants also reported relying on providers as information sources because of their specialized knowledge and expertise.

Radio, Television, and Newspapers

General population participants ranked the mass media low both in amount of information about Medicare and in trust. In discussing their distrust of mass media, participants mentioned perceived sensationalism in media coverage, shallow treatment of news stories, and bias that some participants associated with commercially-provided information. Several participants mentioned political "scare tactics" used by the media, particularly in reporting about Medicare. (Most of the general population focus groups were held during the 1996 Presidential campaign or shortly after the election.) Some general population participants felt differently, however. While acknowledging the shortcomings of radio and television, they said that discriminating viewers and listeners can pick up useful information, perhaps identifying topics of interest that can be pursued through other channels. Some participants also identified particular radio and television programs that they felt were useful and that they trusted.

The Health Care Financing Administration

Besides being listed as a source of information for the card-sort exercises, HCFA was also discussed at the beginning of the focus group sessions, under the topic of "Who is Medicare?" Except for former Federal employees, virtually no one in the general population groups supplied HCFA's name as the agency responsible for Medicare, and only one or two participants per group recognized the name once the moderator said it. With these discussions as background, when the groups got to the card sort exercises, they were generally able to identify the HCFA card properly, although in a few cases there was still some confusion. General population participants ranked HCFA low in terms of the amount of Medicare information received, but high in terms of trust. A few participants described negative experiences with or attitudes towards HCFA. However, a larger portion of participants said they trust information from HCFA because HCFA is the agency responsible for the Medicare program. *While few*

participants said so directly, the underlying inference is that general population participants would be receptive to more information that explicitly identified the Medicare program as the source.

Supplemental Insurance Companies

Some general population participants were not clear on the distinctions between Medicare contractors and supplemental insurance companies. However, virtually all of these participants had some kind of supplemental coverage and were able to identify it during the discussions. General population participants ranked their supplemental insurance companies high both in amount of information provided and in trust. They ranked their supplemental insurance companies highly because they are responsive to requests for information, they answer beneficiaries' questions, and their answers are generally comprehensible.

Community Resources

The Inventory Reports identified community resources as particularly important for beneficiaries with special communication needs. Our focus group results suggest that community groups are not particularly important resources for the general beneficiary population. General population participants ranked community sources low both in amount of information about Medicare and in trust. Most participants seemed to have little experience with these sources, or at least didn't think of them as sources of information about Medicare. With further prompting, participants were able to identify community resources they might use for information.

Organizations Such as AARP and Magazines for Senior Citizens

Many general population focus group participants belonged to AARP, and most of these members were very positive about AARP as a source of information. Although this category of sources was intended to include other advocacy groups, virtually all discussion in this category was devoted to AARP. Participants ranked senior organizations high in amount of information and in trust. Participants said they ranked these organizations highly because the organizations are effective in looking out for the interests of senior citizens. Participants said that AARP's materials are easy to understand and very relevant to their needs. Many beneficiaries who belong to AARP joined well before they became eligible for Medicare, so they are used to receiving information from this resource. In a few general population

groups, participants mentioned losing trust in AARP because of perceived commercial and/or political interests.

Other Sources

Several general population participants mentioned other sources of information about Medicare during the course of the focus group discussions. Former employers were mentioned by a couple of participants, and other sources mentioned included lawyers and the National Association of Retired Federal Employees (NARFE). In discussions about information on ways to stay healthy, health clubs and nutritionists were also mentioned as sources of information.

4.2 Major Findings for African-American Beneficiaries

Family and Friends

According to card sorting results, African-American participants had much the same view of family and friends as beneficiaries from the general population. The following quotations illustrate several reasons mentioned for counting on and trusting information from family and friends.

African-American Participants on Family and Friends
<p>“Do you know who has more information on Medicare more than we do? Our children. Because those are the ones that are going to have to come along and help, if we are incapacitated in any way, in fact if you are diminished in any way, you can’t deal with the health situation period. Be it Medicare, Blue Cross or whatever. Just to follow-up on the claim thing. If someone denies it to question it if they tell you haven’t met your deductible for the year to question it.”</p> <p>“I have two daughters who are nurses.”</p> <p>“My father is 98 and he has his retirement and other insurance and my sisters and I so this is where I get mine because they have experience with these things and I trust them.”</p> <p>“Because they’ve had experience with these companies and I guess it’s because I love them so I trust them.”</p> <p>Participant 1: “I really rely on my daughters because –”</p> <p>Participant 2: “They’re younger.”</p> <p>Participant 1: “. . . no, no, because they work at the place where the information and they will call places that they know I can get information and have it sent to me. And they know how much I get so I’ll have to say well, you know, my salary is such is such or my social security.”</p>

Insurance Companies that Pay Claims for Medicare

African-American participants ranked Medicare contractors somewhat lower on amount of information and much lower on trust than did the general population participants. In part, this difference appears to be the result of confusion between HCFA, the contractors who pay Medicare claims, and supplemental insurers.

African-American Beneficiaries May Be Less Aware of Medicare Contractors

Moderator: Let me ask you this. The one that didn't come up very often was . . . , the insurance companies that pay claims for Medicare. What's the good news about getting information from them, insurance companies that pay claims for Medicare?

Participant: Well, who are they?

Participant: Well, that's a piece of information that we don't have.

Participant: That's right, because we don't.

Doctors, Nurses, or Clinics

African-American participants were similar to beneficiaries from the general population in terms of the opinions about medical providers as sources of information about Medicare. Participants who had well-established relationships with their providers use and trust them as sources of information.

Many African-American Beneficiaries Rely on Their Medical Providers for Information About Medicare

Moderator: Doctors, nurses and clinics, what makes getting information from them a good thing?

Participant: Because they know you.

Participant: . . . I have a doctor I trust. And if I'm in Florida, Georgia or wherever I am, I can call and he's just like a family member. We had chosen one doctor from the list of doctors and he was the best doctor we could pick in that field and that has done more of those operations that we could choose from. I trust my doctor.

Participant: I chose doctors because I have had the same doctors over the years. So if I have a problem I go to that doctor. I have a couple of friends who are in nursing homes and I'm interested in how the doctor is going to explain everything. If he doesn't act like he has time to explain it to me, then I don't like that doctor. I want a doctor who is going to have time and patience with me and those are the kinds of doctors that I have at this time. I get regular checkups. I have a gynecologist, I have a regular medical doctor and I'm really happy with all of them. So that's why I put doctors.

Other African-American Beneficiaries Feel Differently About Their Medical Providers

Participant: No. Sometimes the nurses or their office people, but the doctors just really don't know what they will pay for and what they will not.

Participant: Another reason, some of the doctors have an investment in some of the companies that they're working for. . . .

Participant: Some doctors now have too much authority . . .

Participant: I have [doctors, nurses and clinics] on the bottom. I'll tell you why . . ., simply because I feel that certain things you go to the person who has the area of expertise. The doctor and the clinic may be fine in telling me about my personal health but when someone comes to take care of the payment of the bill, sometimes the doctors and the nurses do not have the information and they send you to someone else and so why would you even start to ask them because they may tell you something that's so far from being accurate, you know, in terms of what you can actually expect that, you know, I would not ask them about it. I mean those are just things in terms of dealing with a health situation.

Radio, Television, and Newspapers

African-American participants were similar to participants from the general population in their opinions about the mass media. Those who didn't trust the mass media stressed perceived inaccuracy and sensationalism, while a minority of participants pointed out the benefits of mass media—they are readily available, up-to-date, and free or very low in cost.

African-American Beneficiaries Don't Trust the Mass Media to Report Accurately

Participant: You can't trust the media because they distort things, they change things around. If something happened on Dog Street, they may say it happened on Cat Street.

Participant: They seem to go for headlines, rather than the substance of it. So it's often misleading. They'll just have some glaring headlines that set you in a panic, only to later find out behind it there was no need for the panic at all. So, it's not reliable. It's just a . . .

Participant: The media, they get things mixed up all the time.

Participant: They scare you to death.

The Health Care Financing Administration

African-American beneficiaries ranked HCFA higher in amount of information and trust than did the general population focus group participants. These rankings were based almost entirely on learning during the focus groups that HCFA was the Federal agency responsible for Medicare. The discussions made it clear that most if not all of the focus group participants had not heard of HCFA before, and that their rankings in the card sort were based on HCFA being a Federal agency.

Most African-Americans Did Not Know HCFA or Confused It With SSA

Participant: The name of the agency doesn't ring a bell. The fact that it's a federal agency [is the reason I trust them].

Participant: I can't buy that, because just because it's a government agency doesn't mean that it's all worthy. I've never heard of it.

Participant: Well, when you get certain information materials through the mail, that acronym might be on there but I never bothered to see what meaning it had, you know, I didn't know exactly what meaning it had.

Moderator: Ok. So we have government and we have the Social Security Administration. Have you heard of the Health Care Financing Administration?

Participant: They're some people I pay money to.

Participant: I heard of them. But I'm not familiar with it.

Participant: Yes, I put down the Health Care Financing Administration. I get literature from in the mail from them.

Moderator: From in the mail. And do you know what that literature is about, what kind of literature it is?

Participant: It's about the HMO, not HMO, but Medicare, that's what it's about.

Participant: Yes, but I never knew what that acronym meant. I've heard of it but I don't know what it means. It could be health care something.

Participant: Well, when you get certain information materials through the mail, that acronym might be on there but I never bothered to see what meaning it had, you know, I didn't know exactly what meaning it had.

Participant: It's usually down at the bottom in small print, the initials, but I never paid it any mind.

Participant: I've heard it. If you go for medical treatment or something and if you use that name they will take you right away.

Participant: So the next time I go I say I'm from that?

Participant: I really don't know but this person told me about it and told me how he did and didn't have to pay for services that he received.

Participant: When I call Social Security, isn't that HCFA?

Participant: I have . . . , the Health Care Financing Administration. Because I told you they cut my check off. Isn't that awful over there in Philadelphia? They wrote me a letter and they cut my personal social security off because he made too much.

Despite Not Knowing the Agency Name, Most (But Not All) African-American Participants Rated HCFA High on Trust

Moderator: Ok, let me ask you. Let's start with . . . , the Health Care Financing Administration. Why do you trust that source for information about Medicare?

Participant: One true thing, I really don't trust any of them.

Moderator: You don't trust any of them.

Participant: Not unless it's one-on-one.

Participant: I mistrust the Medicare financing people, because they'll tell you anything . . . I've been traveling with the government for 40 or 50 years. And I don't trust them behind the back.

Many African-Americans Felt That HCFA Should Be Providing Them With More Information on Medicare

Participant: I'm saying they should know, they should be the most knowledgeable, they're the ones that make the rules and govern it and they administer the program, so they should be and if they don't have the answer they can direct you where you can get the answer.

Moderator: . . .you prefer the agency that administers the programs to give you that information?

Participant: Um, hum.

Participant: Yes.

Participant: Well, who else you gonna trust?

Participant: Well, I feel that they ought to be the experts because they're the ones that have all the information. If there is any information that they don't have, well, then it's entirely possible that they might look at it and see whether or not they can provide or recommend another source of information.

Participant: All of the information that I've ever gotten from them is already typed up. I mean there isn't anything that is their opinion that they write down, it's already typed up so when I ask for it they send it.

Participant: . . . the Health Care Financing Administration is the agency that does Medicare and I have a lot of problems and I would like to know about them and how I go about getting help. A lot of the problems I have is with cholesterol, high blood pressure, arthritis.

Moderator: So you think that's an important source of information?

Participant: Yes.

Supplemental Insurance Companies

African-American beneficiaries ranked supplemental insurers lower on amount of information and on trust in comparison with rankings from participants in the general population groups. The group discussion shed little light on this difference. The differences may be due to including HMOs in the category. Also, one of the quotations below highlights the impact of hassles participants have had with their supplemental insurers.

African-Americans Were Less Positive Toward Supplemental Insurers Than Were Most Other Groups

Participant: The HMO, I don't trust that because I've got to put out money now.

Participant: Oh, um, hum, right. Because then I get something that says they gonna cancel it, you know. . . . Yes, I'm talking about supplementary insurance.

Moderator: Ok, so that's the source you trust the least.

Participant: Right.

Community Resources

Community resources were ranked lowest by African-American beneficiaries. However, a few African-American participants identified specific community resources they rely on for information about Medicare, including churches, senior centers, libraries, and resources available through senior housing communities.

A Few African-American Participants Mentioned Getting Information From Community Sources

Participant: Yeah, I've gone to [a senior center} . . . But, not for health care, for a computer course that they offered. I've been going for line-dancing, bridge, whatever. But, I do pay attention to their bulletin boards and they are very good about posting from different sources the medical information. Whether it's diet, exercise, what-have-you. They'll have a whole health bulletin board there for you to read information. I don't know if they have a staff person to go into detail or not.

Participant: Ok. I belong to a senior citizen club through my church. And usually there is a person that is assigned to gather this information and bring it to the group.

Moderator: Ok. Do they bring it in like a meeting or they have little seminars you can come to, how does that come?

Participant: They bring the pamphlets.

Moderator: Oh, I see and they make it available to you.

Participant: Right.

Participant: My church has the same thing.

Moderator: Your church has the same thing?

Participant: But, I don't go to the meetings, hardly, but we have it.

Participant: I live in senior housing and you can always get straight answers there.

Participant: I like the library because you have a whole source.

Organizations Such as AARP and Magazines for Senior Citizens

Among the African-American participants, AARP was widely and strongly trusted. African-American participants cited the length of their relationship with AARP, the timeliness of its magazine, and its senior citizen advocacy as reasons for their trust.

Other Sources

Other sources of information about Medicare mentioned by African-American participants included employers and the Social Security Administration (SSA). It is important to note that African-American participants reported that they have received no information at all about Medicare.

4.3 Major Findings for Hispanic Beneficiaries

English-speaking and Spanish-speaking Hispanic participants had different reactions to the potential information sources. The following sections describe both sets of results.

Family and Friends

In general, Spanish-speaking participants relied heavily on family members. The dual barriers of language and (in many cases) illiteracy left Spanish-speaking beneficiaries very dependent on English-speaking family members, usually children or grandchildren. In some cases, the family members relied on have limited fluency in English. This further complicates beneficiaries' situations. Spanish-speaking beneficiaries who do not have family or friends willing and able to help, have difficulty obtaining even the most basic information about Medicare.

Many Spanish-Speaking Beneficiaries Rely on Children and Grandchildren

Participant: Well, when I turned 65 years of age, and they send me the Medicare, I didn't have any kind of insurance. And I just decided to find out what it covered so that I could use it. And since I have a daughter that works in Mt. Sinai, she also provides me with information.

Participant: Well, for me, my daughter is the one that takes charge. She is the one who is taking care of all this paperwork. But I never had any problems.

Participant: Well, I don't look for information because if I need anything, my daughter is the one who gets moving on everything. So I don't have any problems in that aspect.

Participant: Well, actually it's from when they called me from here that I had my best chance to communicate. If they tell me that they can. They go and pick me up and that helps a lot. Or if my daughter can come with me, that also helps. But I have learned a fair amount about the program just by listening and asking friends.

Participant: Excuse me. Although I'm a bit illiterate about many things, I bring my son to sit down and explain it to me, because I don't want to make a mistake just because I don't ask the question.

Not All Spanish-Speaking Participants Rely on Their Families

Participant: Well, I chose as the last rank was the family, because they don't have Medicare. They don't have social security.

In contrast, there were few participants in the two English-speaking Hispanic groups who found family and friends to be useful sources of information. While no explicit explanation emerged from the group discussions, it may be that these beneficiaries are less likely than others to have friends and family with informed personal Medicare experience.

Insurance Companies that Pay Claims for Medicare

English-speaking Hispanic participants ranked Medicare contractors about the same as did participants in the general population groups, both in amount of information and in trust.

English-Speaking Hispanic Beneficiaries Ranked Medicare Contractors Fairly High on Amount of Information and Trust

Participant: I always get the 800 number for Medicare and Blue Cross. I don't fool with anything else.

Moderator: So do you think that's convenient for you?

Participant: I think it's very convenient. It's right there in my book. They talk to you just like we would be talking to one another here. So that's why I put F on my second.

Participant: It's a 1-800 number directly. You can talk to them very easy. They're very nice.

Spanish-speaking beneficiaries were almost completely in the dark about Medicare contractors. Almost none of the Spanish-speaking participants had called contractors to get information about a claim. Even if they were aware of contractors, Spanish-speaking beneficiaries often chose not to call because of the expected language barrier.

Spanish-Speaking Beneficiaries Have Little Awareness of Medicare Contractors

Moderator: Would you like the insurance companies to send you more information about Medicare?

Participant: One can get confused. They send so much information that one can get confused. Those that don't know English, they don't know how. You don't know that you need everything in Spanish.

Moderator: Would you also like the insurance company to send you information?

Participant: Well that depends. I think that when I get too much information, then I get all confused.

Participant: And since we don't know English, then it gets worse.

Participant: The problem is, it takes a long time trying to communicate with them. You're on hold. You call. You call. Busy signal. You got to wait. And you wait. And you wait. And you wait. And you wait. They keep you holding forever.

Doctors, Nurses, or Clinics

Medical providers were an important source of Medicare information for Spanish-speaking beneficiaries. The group discussions indicated that these beneficiaries may rely on medical providers for the most basic information, although they are not always satisfied with what the providers seem to know.

Medical Providers Are Often Sources of Very Basic Information for Spanish-Speaking Beneficiaries

Participant: Because I've been there. Because I know them and ask them questions. If I have an examination, I'm going to see and actually speak to the doctor.

Participant: Another important thing is that people who work at the clinics or hospitals are not totally informed.

Participant: The doctor gives—one has to know if Medicare is going to pay him or not.

Participant: In the hospital, with all the doctors that I've seen, it was they who always sent out the information and got the—and collected on the claim, et cetera, et cetera.

Participant: Yes. The thing of it is, is that this doctor that I visited, that I went to see not too long ago, he asked me if I had MediCal and Medicare and I said yes. And he said, I would advise you to stick with these two and then get another company because you're going to have problems here. That's just a piece of advice, he wasn't pressuring me or compelling me to go away. He says that he gave this piece of advice because he's a Latino. He said if you give us the two cards, then keep them and don't look for problems. But I repeat, as I said, I didn't feel pressured or anything but he did give me his opinion.

English-speaking participants also expressed positive attitudes toward providers as resources. They ranked providers especially highly for trust.

Radio, Television, and Newspapers

Spanish-speaking participants reported strongly positive attitudes toward radio and television as sources of information. Particularly in Los Angeles, a variety of stations and programs are available in Spanish, some of which cover health care and social programs. A few participants in the Spanish-language groups found information from radio and television to be confusing or misleading.

Radio and Television are Important Information Sources for Spanish-Speaking Beneficiaries

Participant: Well, the gentleman, Jose, he's on the radio or something. He's on the radio. He has a program on the radio that gives information. You can call them through the telephone and ask any questions.

Participant: I trust the radio the most. I changed. I changed from my doctor. Doctors are just doctors.

Participant: I think that it's on TV where you find out most of the information. All of us get information about Medicare on TV.

Participant: Not too long ago, on K10Q there was a program about Medicare. And they were talking about the benefits everything. [LA]

Participant: And something else that I'd like to say here is that the radio or TV is much more effective, because you're listening and seeing, but when they send you this whole big bunch of papers of advertising, you hardly—you might start looking at it, but between everything that you see and interspersed with bills, you might hear about or read about a program that you're not even aware of.

Participant: Well, this is a radio talk show. They are topics, and there are certain people who are specialized, at least last week. They talked about to the—they talked about the IRS and they had a special guest. Another special guest from Social Security. And there was another person who was specialized in reporting about the department that we're dealing with here. So people would go in and they would offer consultations. They would listen to your question and answer right there.

Some Spanish-Speaking Beneficiaries Find Information From Radio and TV Confusing or Misleading

Moderator: And as far as the information you receive on the radio and TV, is that information clear?

Participant: Well, sometimes yes, but we really don't know. I think once you've listened to it three or four times, then yes.

Participant: It's just that somebody who were to listen to the radio, for example, if I listened I have a doubt. And the person, the expert, whose from the main office might say, or might clarify my question, but if the other people are confused, at least I've been—it's been clarified for me by that person who works there.

Participant: You don't really get information, you just get a brief message. That's it. They don't give the complete information.

Participant: I think that maybe they exaggerate things to get people to become nervous about what we're going to do.

English-speaking participants reacted more positively toward radio, television, and newspapers than most other beneficiary subgroups, but their rankings for trust were still low relative to the strongly positive reactions from Spanish-speaking participants.

English-Speaking Hispanic Beneficiaries Were Fairly Positive About Radio and Television as Information Sources

Participant: What is good about it maybe because it might be the latest thing on the market that can help whatever problem that you might have, or know somebody that has it. Usually TV or the newspapers, you know, TV mostly, will give you the latest thing that's been helping a particular problem, and so you pick that up. Reading the newspapers you'll find out that something has happened where they're evaluating this medicine or that medicine and so you know about that, you know.

The Health Care Financing Administration

Hispanic beneficiaries had diverse reactions to HCFA as a source of information. The two English-speaking Hispanic groups ranked HCFA first in both amount of information and trust, and their rankings were higher than those of any other subgroup or the general population. The discussion revealed some confusion between the carrier and HCFA, but the general feeling was that HCFA was the federal government, and therefore trustworthy.

English-Speaking Hispanic Participants Ranked HCFA Highest for Amount of Information and for Trust

Moderator: Why do you feel that number one would be the Health Care Financing Administration?

Participant: I think it's in their best interest to make sure that —

Moderator: To provide the most information to you.

Participant: Not only that, but I pay them. I don't have social security, but I pay Medicare.

Participant: Because they have more interest. . . . I trust Uncle Sam.

One group of Spanish-speaking participants was very positive about HCFA as an information source. None of the participants in this group had tried to call Medicare, and they reported that most of the information they received about the Medicare program was in English. Most other Spanish-speaking participants were not sure what information they had received from HCFA. Most reported that when information arrives in English only, they cannot use it. Some said they rely on family members to translate English-language material, but this can be a bother both for beneficiaries and their families.

Spanish-Speaking Beneficiaries Were Generally Vague About Information from HCFA

Participant: I put . . . For me it's . . .

Moderator: Okay. The Health Care Financing Administration. Why?

Participant: Because that's going to give me the most precise answer. You know, they're going to give me the most direct answer.

Participant: I'm not sure but I did receive a letter about Medicare and I think they say it comes from Maryland.

Moderator: Nobody has heard about it? In English it is known as "Health Care financing administration". You have heard it in English?

Participant: Yes, yes, yes.

Moderator: OK. When you hear that, what comes to your mind Rosa?

Participant: That it is not doing well. They are doing so many changes.

Participant: I receive things, but I don't read anything. I get letters, but I don't read them. I don't know English, but I'll start to look at things. And sometimes my—one of my children will explain it to me. I sign everything, but my sons sometimes translates things for me.

Participant: Everyone once in a while I'll get some kind of paper in the mail, but the thing of it is, since we don't speak English I don't understand for example. Sometimes they'll send us sheets, though, in English and Spanish.

Moderator: Can you read information that they send you in the mail?

Participant: Yes. As I said, there are some sheets in Spanish and some in English.

Moderator: Do you understand the information when they send it to you in the mail? Is it easy to understand?

Participant: Yes. It's well translated.

Supplemental Insurance Companies

The two English-speaking Hispanic groups ranked supplemental insurers highest on amount of information received and second highest on trust.

Supplemental Insurers Are an Important Information Source for English-Speaking Hispanic Participants

Participant: Well, I get information. I belong to a chapter from AARP, the insurance I'm in.

Participant: I call my supplement. Medicare and Blue Cross.

Participant: Unnecessary billing on both sides. So, but one more thing is we need to be very cautious with it. And I called directly with Humana, because I had not been pleased with it and have everything else. So I said I want to discontinue it. So they told me that it was not—was it insured? No, I guess you'd call it, it's a HMO or something. And they told me that I needed to do this and that. I say, "Why? It's your job to call Medicare," which I did anyway, Medicare, and let them know that it's—that I did call. And then Medicare said, "Recall again, because it doesn't have a . . ." So those things need to be cleared.

Some of the Spanish-speaking Hispanic participants had supplemental insurance. Many others were covered by Medicaid. A minority of those with supplemental coverage viewed the insurers as an important source of information. Most others seemed confused about the distinctions between Medicare, Medicaid, HMOs, and supplemental plans.

Some Spanish-Speaking Beneficiaries With Supplemental Coverage Found Their Insurers Helpful Sources of Information. Others Were Confused

Participant: I don't remember, but to be perfectly honest I don't remember. When my daughter found some information, and she told me, you know, "Why don't you choose Prudential," because Prudential was best for her.

Moderator: Okay. And who's Prudential?

Participant: Well, I'm going to say it's an insurance.

Participant: I have Prudential.

Moderator: Would you call insurance?

Participant: Yes. That's the first person I call.

Participant: I put my insurance company, because if you don't have an insurance company how are you going to the doctor.

Moderator: You mean your supplemental insurance?

Participant: Yes.

...

Participant: Yes, supplementary. This is one program in which you have to pay, which does not cover Medicare, Aetna secondary is what I have. They said that they would give me information, but it was not very helpful.

Moderator: How about your supplementary insurance plan, do you feel comfortable receiving information from them?

Group: Yes.

Group: Supplementary?

Moderator: Well, if you were to get information, do you think that would be a good place to get it?

Group: Yes.

Community Resources

Spanish-speaking Hispanic participants reported more use of community information resources than did participants from any other beneficiary subpopulations. In one focus group, participants mentioned the housing project where many of them lived as an important resource. Among Spanish-speaking participants, women seemed more likely than men to use community information resources.

Spanish-Speaking Beneficiaries Get Information From Community Sources

Participant: I go to the church. They have a center and there they give me information. They have lots of papers that I can read.

Participant: There is information at a religious center I go to. They have a lot of free written information one can take home.

Participant: People in the community I have the least confidence in.

English-speaking Hispanic participants ranked people in the community as lowest in both amount of information and trust. Subsequent discussions among English-speaking participants did not reveal any use of community sources. It is important to note that the two English-speaking Hispanic focus groups were conducted in the same city. Therefore, it is difficult to interpret this finding.

Organizations Such as AARP and Magazines for Senior Citizens

Spanish-speaking beneficiaries were generally unfamiliar with AARP, and so did not view it as an important source of information about Medicare.

Most Spanish-Speaking Beneficiaries Were Unfamiliar With AARP

Participant: I put number one H, because I receive a lot of information from magazines for senior citizens.

Participant: Wait a minute. I received a paper from the AARP, but I don't know what it is. I mean I didn't read it because it was in English. I say it's an HMO.

Moderator: Does anybody know what that is, AARP? Does anybody know? What is it?

Participant: This is the first time I've heard of it.

Moderator: It's for retired people. It gives them discounts for hotels, trips.

Participant: I don't think it has anything to do at all with Medicare.

Moderator: Honestly I don't know.

Participant: I think it's an insurance company.

Participant: That's what I thought it was. And since I was coming over here, I didn't take the time to read it.

English-speaking Hispanic participants also ranked AARP and other senior citizens groups low on both amount of information and trust. A few of the English-speaking Hispanic participants were members of AARP and they ranked it as a useful resource.

Few English-Speaking Hispanic Participants Ranked AARP Highly
Participant: The AARP sends you a magazine that gets you all the information.
Participant: Yeah, so I don't—just if there's any changes that they're working on in the legislation is what I've found in the—what is it, A Modern Maturity?

Other Sources

Several Spanish-speaking participants mentioned Social Security as a source of Medicare information by Spanish-speaking participants. Some of the Spanish-speaking beneficiaries also confused Medicare and Medicaid in thinking about how they receive information. English-speaking participants did not mention any additional information resources.

4.4 Major Findings for Dually Eligible Beneficiaries

Family and Friends

Participants who were dually eligible for Medicare and Medicaid were less likely than general population participants to rank family and friends as important information sources. Dually eligible participants were very similar to the general population in their rankings of trust. The following quotations illustrate reactions to family and friends as sources of information.

Some Positive Comments From Dually Eligible Beneficiaries on Family and Friends
Participant : For me, it's friends that tell me about it that got it before, a few years before. So they're the ones that told me about it.
Participant : I think what you were saying, they tell you what treatments they've had or surgeries. If you're a doctor with a similar problem, if he tells you one thing and doesn't mention these other things these people told you. So instead of asking the doctor you tell the doctor how about this or that or all these others. Then you've got him thinking and maybe he'll do more for you because you got this information from the people that you know.
Participant: My daughter was a nurse in doctor's office, so I get everything from her.

The Other Side of the Picture From Dually Eligible Beneficiaries

Participant: Friends and family? No way.

Participant: I wouldn't go to a friend and ask them, "Well, how do I do this and that or whatever." If I can't trust my insurance company or your, you know, whoever is helping you, I mean, who else can you deal with. No, they won't pay that, if you ask your friends or your neighbor or somebody.

Participant: Going to friends and relatives, you've got too many answers. None of them is really authoritative.

Insurance Companies that Pay Claims for Medicare

Dually eligible beneficiaries ranked Medicare contractors lower in amount of information and in trust than did participants in the general population focus groups. Dually eligible beneficiaries often do not get EOMB forms, and they often do not have out-of-pocket expenses, so they are less likely to have experience with Medicare contractors than other beneficiaries. Discussions revealed confusion about the roles of Medicare contractors.

Dually Eligible Beneficiaries Have Little Experience with Medicare Contractors

Participant: A lot of times I call them, there's a place down the road that has a Blue Cross, you know, and I call when I want information. So I went to a doctor there and had tests done on my heart and they sent me the bill and I called them and got the information and they got it right away. It was pretty good.

Participant: They usually explain to you before they're going to bill you, where they're going to send it to, and if it can be billed to them for the full amount. Because, like I said, not that many people read it in the magazines or read at all. I do read, you know, and I have seen what he's talking about, but I go with my insurance company that pay the claims for Medicare.

Participant: Well, really the insurance companies, they're talking to clerks who are insurance-oriented, not necessarily illness-oriented. They don't know—they have a chart to go by, and they go by that chart, whether you're a regular. For instance, I had one tell me I never had cancer. She just said, "You never had cancer." I had 35 operations for cancer, but "You never had cancer." Because I didn't go according to that chart. So, it isn't that they try to be wrong, but they just don't know.

Participant: I put down B because I've never had—I have Medicare and Medicaid. And I've never had any problems. Several of my friends are always saying that they have a lot of problems when they try to follow with their insurance. And they have to go through a lot of, you know, a lot of problems to get through, you know. I, myself, have never experienced that.

Doctors, Nurses, or Clinics

Dually eligible participants ranked medical providers highest both for amount of information received and for trust. Generally, dually eligible beneficiaries rely less on official or bureaucratic channels for information than other beneficiaries. Their rankings of medical providers may reflect the importance of an in-person contact, as well as providers' uninvolved involvement with eligibility and other bureaucratic considerations.

Dually Eligible Beneficiaries Rely on Medical Providers for Information

Moderator: What kind of information about Medicare did you get from doctors?

Participant: What you can get and what you can't.

Participant: Well for me, . . . , I didn't have to go anywhere, I just called. In fact, I had a nurse come at the time I was sick in the hospital, she came to my house and I asked her and she explained it.

Participant: Well, I mean, this is supposed to be how you get your information about it.

Moderator: About Medicare.

Participant: Yeah. Sometimes I say, "Well, I can't afford that." And then they ask, "Well, don't you have Medicare or Medicaid?" I say, "Yes." They say, "Well, they will pay for it."

Participant: I'll rely on my doctor. When I have any questions, I'm going to call him first.

Participant: He's always busy too. So you can't be bothering him with every question you want to know.

Radio, Television, and Newspapers

Dually eligible participants ranked mass media lowest of all sources on both amount of information received and trust, but the range of mean rankings from highest to lowest was relatively narrow indicating low agreement. Subsequent discussions revealed negative attitudes without much supportive detail.

Dually Eligible Beneficiaries Generally Rank Mass Media Relatively Low as an Information Source

Participant: Television specials, you know, they keep repeating it over and over again and you get the message.

Participant: I have switched from one channel to the other, and they're both talking about the same subject, but completely different, completely different, unless I'm hearing different. This could be.

Participant: I had radio, television and newspapers. I don't use them as a source. It's there. I'm aware of what they're relaying, but I always get another opinion. It's my least important input.

The Health Care Financing Administration

Dually eligible beneficiaries ranked HCFA lower on trust than any other study population. Again, the range of mean rankings for trust was narrow, indicating low agreement. Dually eligible beneficiaries often had trouble distinguishing between Medicare and Medicaid, and they were less likely than most other beneficiaries to have had contacts with the Medicare program because of a claim. For most beneficiary subpopulations, learning that HCFA is the Federal agency responsible for Medicare led to high rankings for trust in the card sort for dually eligible participants. This was not true for dually eligible participants. Dually eligible beneficiaries reported they are grateful for their health care coverage; they are also particularly concerned about changes in the Medicare and Medicaid programs and effects of changes on their own eligibility or benefits.

Dually Eligible Participants Ranked HCFA Low in Trust

Moderator: Okay. Do you know who runs the Medicare program, the name of the agency? Have you ever heard of the Health Care Financing Administration?

Participant: That's the one that's going to be in trouble.

And as for the E, the Health Care Financing Administration. They, too, I feel are removed. They're too far removed from my particular situation where I am. And that's why.

Participant: I put down E, because that's who you said printed the pamphlets, was that office. And that's all I've ever—I've only been on it recently. And I've only gone to the doctor one time. So, all the information I got was off of this pamphlet, the literature that they furnished.

Participant: I never heard of them.

Moderator: You never heard of the Health Care Financing Administration. Okay.

Participant: No one ever says, "I represent the Health Care financing Administration."

Supplemental Insurance Companies

For dually eligible participants, the "supplemental insurance" category included Medicaid, and may also include HMOs and private supplemental plans. Rankings for amount of information and trust were comparable to those of the general population groups. In San Antonio, the dually eligible group talked about HMO marketing—virtually all the group members were aware of it and had been approached.

For Dually Eligible Participants, “Supplemental Insurance” Meant Medicaid; For Some, It Also Included HMOs and Private Supplemental Insurers

Participant: One of these HMOs sent out notices for them having lunches or breakfasts and to various restaurants . . . , to give out information about the HMO. And I guess you could ask questions, but I haven’t gone to any of them. As a matter of fact, I got one just this week.
--

Participant: Yes. One lady wanted me to—some insurance person wanted me to get out of Medicare and Medicaid and join this thing. I said, “No, because I like my doctor and I want to have the same doctor all the time.” This other, where you go into their clinics, and you get any doctor that’s available with that.
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Community Resources

Although dually eligible participants ranked community sources toward the low end on both amount of information and trust, their rankings were higher than those of the general population groups. In subsequent discussions, several participants mentioned specific community sources where they received information.

Some Dually Eligible Beneficiaries Found Community Sources Helpful

Participant: Anything we get, we post it on the bulletin board.

Participant: That’s what I was going to say. We do allow pamphlets and different information . . .
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Participant: And at different months at our association meeting, we’ll have a speaker come in, like our—from the DNA, or from any one of the health insurance companies. They’ll come in. And they speak quite readily on Medicare and Medicaid and whatnot. And we do get some information from them.
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Participant: I live in a building where they do have a senior center. And they have meetings from time to time. They don’t bring it to the building where I live. You have to go to the senior center to get it.
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Participant: People in the community, such as senior centers. The . . . area counsel on aging is a great source of information.

Participant: The senior centers, the libraries, these people give not just necessarily information, but ways to get information.
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Organizations Such as AARP and Magazines for Senior Citizens

Dually eligible beneficiaries rankings for AARP and other senior citizens' groups were similar to rankings from the general population. Many appeared to be members of AARP.

AARP and Senior Citizens' Groups Were Important Information Sources for Dually Eligible Participants

Moderator: Is it AARP specifically that's been important for you?

Participant: Organizations and so forth, magazines and senior citizens papers.

Participant: I have H, AARP. Right now I don't have any health problems so I haven't had to deal with all of this yet. So I'm reading up on it in case I have to.

Participant: Well, I've been getting this magazine for almost five years. And there is a page on Medicare in every one of those magazines, a 1-800 number, what do you want to know, call us. And I have called many times, but the times that I have called, I've gotten the correct answer, and a very helpful answer. And you know how sometimes you talk to your doctor and they give you these long name and things like that. You don't have—you have no idea what they said, but the people talk at your level and let you understand what they're saying. I'm very comfortable with them.

4.5 Major Findings for Rural Beneficiaries

Family and Friends

Focus group participants from rural areas ranked family and friends much lower on amount of information received than did participants from the general population. Rural beneficiaries also ranked friends and family somewhat lower in trust. Rural residents may be more isolated from family and friends, but the discussions also showed a strong sense of self-sufficiency and personal privacy.

Rural Residents Tend to Value Privacy and Be Self-Sufficient

Participant: I love my family. They love me too, but I live alone. I take care of myself.

Participant: Sometimes they get too nosy.

Participant: They want to know your business.

Participant: I don't refer to my family because as long as I can handle my own problems, I don't want to burden them. They have their own problems. So I won't burden them with mine. There are other sources besides family. . . I wouldn't say they're trustworthy, but . . .

Participant: My family, forget it. They're all grown, but I told them the other day, mom is not going to be here all your life, you'd better make up your mind what you're going to do after mom is not here.

A Few Rural Residents Received Information From Family and Friends

Participant: I seems like I learn more from people who have had something involved with Medicare, or a problem or something who—that's number two.

Participant: Well, I think that sometimes a family member will tell you their experience and yours might parallel theirs. And they had their experience, a medical experience, some years ago. And maybe not years ago, but the point is you can benefit from their experience and their—the things they went through to get their case taken care of and paid for. So I personally have benefited from a family member telling me about his experience.

Insurance Companies that Pay Claims for Medicare

Rural beneficiaries emphatically ranked Medicare contractors high for amount of information about Medicare and high for trust. Rural residents may rely more on the telephone as a way to get information than other beneficiaries. Rural participants seemed relatively pleased with the service they received from the contractors' 800 numbers.

Rural Residents Received the Most Information from Medicare Contractors

Participant: They gave me the specific information that I ask for. Even when I got a bill that they had paid for a town that I'd never been in and a hospital I'd never heard of. I called them and it was resolved within weeks. I made one telephone call. I said I've never been to that town. It was in the same state where I had got food poisoning and had been to another hospital there, but, somehow or another it ended up, I got the statement. I just said, I've never been there, this is not mine.

Participant: Yes, very polite and helped me with everything I needed to know.

Doctors, Nurses, or Clinics

Beneficiaries residing in rural areas generally ranked official bureaucratic sources highly, but they also ranked medical providers highly for amount of information and for trust. Again, the personal interaction seemed important.

Beneficiaries in Rural Areas Were Generally Positive About Medical Providers as Sources of Medicare Information

Participant: If you can't trust your doctor, you might as well not trust anybody.

Participant: Well, I picked C because if you don't trust your doctors and nurses, who are you going to trust, because he knows what's best for you. And he usually tells you, you know, about paying and all. My doctors do, anyway.

Participant: I have C for my—for the first, because I don't have any other insurance but Medicare and the doctors offices. They handle all my forms and send in the information. I pay my bills.

Participant: The best source of information was the hospital designated Medicare person that I spoke to, by all means.

Participant: Well, he's about the only one you really ever get to sit down and talk with, or meet face to face to talk with, not unless its his secretary.

Radio, Television, and Newspapers

Rural residents were similar to participants from the general population in their rankings of and attitudes towards the mass media. While there were some positive notes, the general view was that information from mass media sources is contradictory and not to be trusted.

Rural Beneficiaries Generally Do Not Trust the Mass Media

Participant: Well, I've seen a cataract operation on PBS, and a heart by-pass operation, but these you can't buy in a video store. I wouldn't want to, but that's good information.

Participant: You can't believe anything they say.

Participant: Discrepancies I guess is the polite way of putting it.

Participant: I think they subtly slant the interpretation of the news to their way of thinking. And you can't pin them down on it because they do it so subtly that you really have to be awake.

Participant: I have a thing about TV and radio and health programs. I get so sick I turn it off.

Participant: Well, you think you have it pretty well understood and then they come up with something else.

Participant: I mean, it seem to me they conflict all the time.

Participant: You get one little piece.

Participant: Well, they just give you the headlines. But when you read the bottom line, real fine print, that's when you get in trouble.

The Health Care Financing Administration

Rural participants ranked HCFA highly in both amount of information and trust. The rankings may be a bit misleading though. As one participant said, “We don’t have much choice. We kind of have to trust them.” The rural participants also had some complaints about getting information from the Medicare program. These complaints were at least as much about Medicare contractors as they were about HCFA. (Like most other participants, the rural beneficiaries did not distinguish between Medicare contractors and HCFA when talking about their efforts to get information.)

Rural Participants Were Generally Not Familiar With HCFA

Participant: It’s actually a security for each one of us.

Participant: Well, this Health Care Financing Group, apparently that’s neutral. In the previous Medicare handbooks, they didn’t mention that group. So it apparently has just been established.

Participant: On E, I wanted to ask you a question. The Health Care Financing Administration. I really don’t know what that is. I assume the Social Security office.

Participant: The Healthcare Financing Administration, is that social security?

Rural Beneficiaries Trust HCFA, But With Qualifications

Participant: Well, I have . . . , Health Care Financing. They’re the ones who call the shots. So I figure they would give me the best information, because they run the show.

Participant: That’s a good reason. They’re the top. If you can’t trust them, who are you going to trust?

Participant: I never had any dealings with them, so I—but I would assume it’s trustworthy.

Participant: Well in my case, it is the little I know about it. It’s difficult to make this decision. I have never called them for any reason. The people who I have the service from take care of the billing. Everything has been quite satisfactory. If there is a complaint about the service from Medicare, I don’t have one. I’ve never had the occasion to call anyone, call the person, track them down. I just haven’t.

Participant: We don’t have much choice. We kind of have to trust them.

Participant: ...That’s why I guess I put (HCFA) first. They are the ones who administer it and basically you have to accept that and trust they are correct. The others are someone’s interpretation of what it is. They may be correct but they may not. There is where we get all these problems. One says one thing, this is what it is and the other one says no it isn’t. It just goes back and forth. It seems to me that maybe one of the things here that social security, Medicare, ought to do, is a better provider to these other groups—the insurance companies, the providers, the HMOs the physicians . . .

Participant: I have [HCFA] . . . The handbook . . . Because it does contain, you know, a lot of information that we need.

Participant: That’s mine, too, because they pay for everything.

Participant: And if you call them and try to find out anything, someone, I don’t remember who, mentioned it. If you talk to three different people, you get three entirely different answers.

Supplemental Insurance Companies

Rural beneficiaries' rankings distinguished clearly between Medicare contractors and supplemental insurers. Supplemental insurers were ranked much lower than carriers on trust, and the rural beneficiaries rankings of supplemental insurers were much lower than rankings from general population participants. The differences may be related to the value of personal privacy and the suspicion of commercial endeavors among rural beneficiaries.

Rural Beneficiaries Appeared Suspicious of Supplemental Insurers

Moderator: Well, it's interesting to me that you had the contracting insurance companies at the top and your supplemental insurance company at the bottom.

Participant: I guess that's because I don't know anything about them. I'm just naturally suspicious of them, I think, for whatever reason.

Moderator: Is there a particular reason why you don't talk to them [supplemental insurance]?

Participant: It's none of their business.

Participant: I'm satisfied with the way my [claims] are handled, so I don't ask anybody else how they handle theirs.

Participant: They're too high, but they have the information also.

Participant: Last year I was invited to—my husband and I were invited to one of the motels to a meeting that was being sponsored by an insurance company. That's what it really ended up being. And, of course, they compare—they talked about the Medicare, you know, being ***. And also, then they brought up what they could offer you, you know, as a supplement. And we received a lot of information there.

Community Resources

Rural residents ranked community sources somewhat lower than general population participants did, both in terms of amount of information and in terms of trust. Again, privacy was an issue for rural residents. They may also have less access to some kinds of community resources than people living in more heavily populated areas.

Rural Residents Made Little Use of Community Resources for Information About Medicare

Participant: Generally they really don't know that much about it. It's what somebody told them that they said and so on. I suppose actually I could have [community resources] and [friends and family] equal. One has to come before the other so I had [community resources] as last. But, all these others are someone's interpretation of what the plan is.

Participant: Because I don't have contact with them. So I have no knowledge of it. That's why several of these I would not—I don't come in contact with them.

Participant: But I feel like he does. Communities, I guess, because you don't see those people. You don't talk to them about health insurance. The only ones you talk about those personal things with is your friends.

Participant: Well, . . . such as senior citizen groups and whatever. I don't—I never go too public with the information . . .

Organizations Such as AARP and Magazines for Senior Citizens

Rural beneficiaries were less enthusiastic about AARP than participants from other beneficiary subpopulations, but many still found it an important source of information about Medicare.

Rural Beneficiaries Saw AARP as an Important Information Source, But They Were Less Enthusiastic Than Members of Other Subgroups

Participant: Although AARP is the best all around. I don't have supplemental, I didn't buy it. So now with all these problems, you can go to AARP and get coverage without question. Blue Cross/Blue Shield will ask questions.

Participant: Well, I think they provide good information. I just don't use their information . . . because I'm perfectly satisfied with Medicare and with the doctors and nurses.

Participant: This is not a disadvantage, but I think I have noticed here of late that they are beginning to become more political than they were before. They're beginning to, I would say, stick their nose in where it's not necessary to do, but it's AARP. It's not a political group.

Participant: I don't like the long wait. It's a time frame factor with me. . . . When I want information, I want it now, or tomorrow.

Participant: The AARP puts out Modern Maturity and it's got nice articles in there.

Participant: Well, AARP. I get from that. . . . That's what most of these people do is belong to that association. You get a lot of information from there.

Other Sources

Rural beneficiaries mentioned former employers and pharmacists as other information sources, as illustrated in the quotations below.

Rural Beneficiaries Mentioned Other Sources of Information

Participant: . . .after my husband retired, whenever we get all of this gobbly goop, he just goes to the college and says, “Here.” And they have a resource person down there who will take all this stuff. And she’ll call back a week or so later and she’ll say, “Forget it. If they send you any more bills, bring them. Forget it and let me sort through it.” So she’s the best one that will sort this stuff out.

Moderator: And you say the college. Was that the employer?

Participant: Right. And it’s a service they offer. They help you sort through all of this.

Participant: There was some things on this . . . things like that, a local druggist that we deal with has a computer with all the medicine that you take in it. And if the doctor gives you a new prescription, he’ll tell you if it conflicts with anything you’ve been taking or have taken. And it’s a protection. I don’t think you get it from a lot of places.

4.6 Major Findings for 64-Year-Olds About to Enroll in Medicare

Family and Friends

Family and friends are a particularly important source of information for people about to enroll in the Medicare. Many participants mentioned a spouse or other close relative who recently began receiving Medicare. Many people about to enroll, like some younger beneficiaries, received information about Medicare because they were involved in their parents’ interactions with the program.

People About to Enroll in Medicare Rely Heavily on Family and Friends for Information

Participant: They are the ones that are involved in this. They can tell me what their experiences are, what's happening. If I read something, I have to deduce from that what might happen or what I understand of it. These people are living it. Some good situations and some not so good situations.

Participant: Well, friends are around the same age, we're all going through it or have been through it in the past year or two. It's a big issue. It's a big topic, health care. So, we trust each other because we talk about it and one person will read about it and another person will read something else and we'll compare.

Participant: Well, I've got to decide which—and that's hard to do, which supplemental thing. Some day I'm going to go over to a friend of mine and discuss it with him.

Moderator: And she's made the decision already for herself?

Participant: Oh, no. She's younger, but between the two of us, I figure just talking about it I'll be able to make up my mind.

Participant: And I live in Century Village which the average age is 60 to 90 so you know there is always a conversation there around the pool, you know pro and con with that.

Participant: I'd like to believe the people that I talk to the most.

Participant: I helped my mother when she had it for a while. And both my mother and father did not like insurance companies very well when they got older, because they did not—and one of them Blue Cross. And one of them was Banker's Trust. And they did not like what they did. And I'm not sure exactly what all it was, but they just stuck to Medicare period. That was it. Medicare and they didn't have any supplemental at all. They got along fine with all the different things that they had wrong. And they had a lot. My Dad lived to about 85. My mother was 91. We did alright. . .

Some People About to Enroll Feel Differently About Family and Friends

Participant : They can't give specific, they would have to give generalized types of things. They aren't in a position to say we advise you to get such and such.

Participant: All my friends are really younger than I am, so they haven't got the information I got.

Participant: Well, just discussing various aspects of Medicare and what not with them and their friends, I feel that they don't know very much.

Participant: It's only in the realm of their experience. And if they haven't had any experience, or haven't had any problems then they really don't know.

Insurance Companies that Pay Claims for Medicare

People who have not yet enrolled in Medicare have had no interactions with contractors about their own benefits, so it is not surprising that participants about to enroll in Medicare ranked contractors relatively low for amount of information and trust. Some participants had previous contact with contractors because of family members' experiences.

Most People About to Enroll Have No Experience with Medicare Contractors

Participant: Since we are not on this yet, I have no contact with them. They wouldn't appreciate me calling and saying what are you going to do in 11 months.

Participant: I put down B because I've never heard of them.

Some People About to Enroll Have Learned About Medicare Contractors Because of Family Members' Experiences

Participant: I've got insurance companies that pay claims for Medicare.

Moderator: Okay. What makes you say that?

Participant: Because my mother, who passed away in 1990, she had Medicare. And then now through my husband, the insurance companies, Blue Cross/Blue Shield, has given us a lot of information. Blue Cross/Blue Shield of Texas. There are so many Blue Cross/Blue Shields. This is Texas, it's government, from the federal government.

Moderator: What makes you trust them?

Participant: Because they have been very fair with us, the experience I've had, through my husband, through my mother. And all the information that I've had. Insurance companies that have paid claims for me, because they've given me a lot of information, and fair, truthful. And I think *** was the right thing that I trusted.

A Few People About to Enroll Had Negative Impressions or Misperceptions About Medicare Contractors

Participant: They don't tell you the same story twice. And I don't know how you can trust them. They don't tell the same story twice.

Participant: Yeah, but let me ask you a question. Don't they set the scale for the payments that they make?

Participant: They also tell you how many days that you can be sick with such and such. And sometimes, for some people it works real well. And for others it does not.

Doctors, Nurses, or Clinics

Somewhat surprisingly, participants about to enroll in Medicare ranked medical providers last by a considerable margin both in amount of information about Medicare and in trust. The discussions elaborated on these attitudes, but did not provide insight into why participants about to enroll in Medicare were so different from beneficiaries in their attitudes toward providers.

People About to Enroll Don't Find Medical Providers Helpful in Getting Information About Medicare

Participant: They really don't know. They have half of the story. And they try to help you, and they're more hindrant than they are helpful.

Participant: They don't care . . .

Participant: They're payment oriented. That's all.

Participant: That's the people that the doctors hire to work for them. They don't know what they're talking about, mostly. You very rarely can get a doctor to give you an answer on that.

Participant: It's probably the staff. The doctor hires the staff, because he doesn't know—he can't keep up with all of this.

Participant: He sloughs it off on the staff, and the staff really don't know—have the knowledge.

Moderator: What about the doctors and nurses? What are the good and bad points about them?

Participant: There is a kind of fiction that a lot of times when they carefully explain things to you but they usually turn you over to other kind of professionals or they don't have the amount of time to . . .

Participant: They just don't know.

Participant: They just don't have the knowledge . . .

Participant: They just don't know.

Participant: Most of them are very young people and they just aren't concerned. They are not really geared to the seniors or . . .

Participant: In the HMO's, some of them have between 7 and 10 minutes allotted to a patient. This is actually what they have, so they don't spend a great deal of time talking. They may turn you over to a nurse who may fill in some of the blanks.

Group: They don't get enough money so they don't want to bother with you.

Participant: They just—they don't talk to you. They don't talk to you about anything, much less talk to you about Medicare.

Participant: Well, you never hear from them unless they don't pay your bill. And then, you know, if they don't—if it's not something that's not covered or something, then you hear. The doctor should have perhaps told you it wasn't covered, but they don't tell you that. It's only after the fact when Medicare rejects it, then you hear from somebody there at the doctor's office saying that Medicare did not cover that.

Participant: And the other thing to watch for too, as far as the Medicare, is to when you do get the bill, to watch what they're charging you for all down the list, because it's not too accurate too many times.

Radio, Television, and Newspapers

Participants about to enroll in Medicare were very similar to participants from the general beneficiary populations in their rankings of mass media sources. Subsequent discussions produced more positive comments than was typical in groups with other beneficiary subpopulations.

Many Participants About to Enroll Reported Negative Perceptions of the Mass Media

Participant: I agree 100 percent. I've never gotten any good information about Medicare except they are going to go broke in 3-1/2 hours. I disregard, generally, the radio, TV and newspaper only except to maybe use it as a trigger for a concern.

Participant: Most times they are trying to sell you something. They aren't going to tell you the truth. They're going to look at Ed McMann in a big sweater telling me what to buy.

Participant: I just don't think they give you any information that you need.

Group: That's true. They give you a big build up and then when it comes right down to the nitty gritty it's not there.

Group: Yes. They tell you what you want to hear. They tell you what you hope to hear.

Some People About to Enroll Had More Positive Things to Say About the Mass Media

Participant: I get a lot of information from the newspaper.

Participant: Yes. That's where I get a lot of information.

Participant: I had secondary. I put . . . , radio, television and newspapers. And I read Consumer Reports and it has a lot of information on that—Consumer Reports. So primarily newspapers, various periodicals, medical and magazines of that sort. Also AARP. I read the AARP paper. I put that second, where I get information as to what Medicare will cover and what they don't cover and what supplementals cover and what they don't cover, et cetera.

Participant: Why I media down as one of my most—for most information, they tell you the changes in the programs, if there's going to be a change or there's legislation to make a change or something of that sort, then you're aware that something is happening or is going to happen. And that, I think, is important.

Participant: You can tell in the news stuff that's coming up in therapy, in medications, and the medications that some people are taking, what's dangerous. I don't know. I think the news is pretty good.

The Health Care Financing Administration

Focus group participants about to enroll in Medicare were all 64 years old. Some of them had received information about Medicare; others had not. Like most of the current beneficiaries, they did not recognize the name “HCFA.” Nonetheless, they ranked HCFA substantially higher than the general beneficiary population groups in both amount of information and trust. These high rankings are probably due in part to the fact that this population has not yet been involved with carriers and supplemental insurers.

People About to Enroll Have Not Heard of HCFA

Moderator: If I say Health Care Financing Administration, has anyone heard of that, Health Care Financing Administration?

Participant: I guess I’ve heard the words. I’ve never given any thought to what it was.

Moderator: HCFA. What is that?

Participant: Household Finance Corporation.

People About to Enroll Are Eager to Receive Information from HCFA

Participant: The government. Again, this is where you get information. You get a booklet and you read what the booklet says. It will say what your payment is, exactly to the penny. It says what your deductibles are. You can’t get more specific than that. Now, there are generalities that you need to get information, but I know what the payments are. I know the deductibles. So to me, when it comes to information for that, I’d have to say government.

Participant: I have to add to that, the information is reliable. If you talk to friends they may have a different interpretation of the benefits, they may not be aware of all the benefits that you are entitled to. I would say the most valuable is the Medicare.

Group: I would like them to send me information that tells me the best way, the best insurance to get that. I am pretty old and I don’t know all of things and I am not out there in the world where I get all of it. I would like for them to send the best way, the best insurance, the best way to go to get this insurance that I really need that is not going to cost me half of my pay that I get every month.

Supplemental Insurance Companies

People about to enroll in Medicare often have no direct experience with supplemental insurers. However, many have explored their options or have even made decisions in anticipation of Medicare eligibility. Thus, their exposure to supplemental carriers is more likely through marketing than through actual performance. Some have learned about supplemental insurers through hearsay. These factors may contribute to the generally low rankings people about to enroll gave to supplemental insurers—both on amount of information and on trust.

People About to Enroll Know About Supplemental Insurers and HMOs Through Marketing Efforts and Hearsay

Group: Calling you up and asking you to join them. They send you letters and big packages like this in the mail. And that's about all. Blue Cross Blue Shield or Pru-Care all of them like that send you something in the mail.

Group: But see it must be the closer you get because I haven't gotten anything yet so I am kind of different.

Group: It's a weekly thing for me now.

Group: The only thing I ever received was from Health Options.

Group: And my husband is a retired John Hancock Agent so we get things from the insurance company explaining things for his Medicare. I don't have any of that yet but that's how that works.

Moderator: You were you thinking, for those of you who put the insurance companies at the bottom, were you thinking of your own insurance or the insurance companies that have are selling to you.

Group: I was thinking about what I heard about the insurance companies, the HMOs. I've heard very bad things about them and I wouldn't trust them. And about the law suits going on. I read in the newspaper about the law suits so that's why they are on the bottom.

Group: I live in a senior citizen housing and they always have a rep coming down from all the various companies. And they give these little talks and refreshments and stuff and that's how you hear.

Participant: Really, you don't have to go out and ask for information, because every day or every two or three times a week you get some kind of insurance through the mail.

Participant: Yeah.

Moderator: So what kinds of things are you getting?

Participant: A lot of insurance claiming they're low and *** secure a horizon. All kinds—I bet there's a stack of letters . . .

Participant: Deciding what is best for you is sometimes difficult, because you have so much to choose from.

Participant: I have found that they even sent information to my daughter.

Participant: You know, saying you were 65, or you want to get HMO, some kind of HMO? I mean, we have had stacks and stacks of mail sent to my daughter and my husband. My husband's already in there.

Moderator: Let me make sure I understand. Do they send it to your daughter by mistake, or because they want to get you through your daughter?

Participant: I really don't know. I don't know. And we've told them over and over by phone and otherwise. My daughter is not eligible for Medicare. She doesn't live here.

Participant: The same thing happens to me. My son keeps getting mail to my house from Humana and various HMOs, saying, "Dear Medicare recipient," you know. And he's 37 years old. So it's like having movies or somewhere, you know, to talk about supplemental insurance.

Community Resources

A few participants about to enroll in Medicare mentioned using community sources for information about Medicare. They ranked community resources somewhat higher than did the general population participants.

People About to Enroll Have Received Some Information About Medicare From Community Sources

Participant: I've gone to a few seminars at the senior center, not pertaining to this, but long-term care and all these other options that you have to start thinking about now. Just in general, talking to people who have gone through it. They all have the same concerns.

Group: Well where I live is a retirement center so there is always booklets out in Century Village. Always doctors coming or lawyers or people representing things so that would be for me would be right there. And we have a library yeah.

Participant: Well, I put the last one, people in your community such as senior citizen centers, churches and libraries, because everybody is different. Everybody's situation is different.

Participant: That's what I put.

Participant: And that's the last one, because I don't communicate with the senior citizens at my church that much, you know, or the people at the library. I never go to the library. So that's going to be the last situation that I got, people.

Moderator: Did you have similar reasons?

Participant: Yes. I just don't, you know, I don't know that they're any more knowledgeable [about these things] than I would be. So as a result, I don't rely on their advice.

Organizations Such as AARP and Magazines for Senior Citizens

Participants about to enroll in Medicare were very similar to general population participants in their rankings of AARP and other senior citizens' groups. Many were members of AARP, but some had reservations about the organization. AARP has one advantage over the other information sources participants discussed; since the membership age is 55 years, individuals about to enroll in Medicare have more opportunities for practical exposure to AARP.

People About to Enroll Viewed AARP as an Important Information Source, With Some Reservations

Participant: I don't like the slants. Bottom line, I think everyone has an ax to grind and an example, I'm a member of AARP I work as a volunteer in AARP but AARP slants information going out. I think if everyone here is a member of AARP they get this bulletin and so forth. It is very slanted.

Participant: I do subscribe to AARP and usually, whether it's biased or not, they are pretty much up to date on what is happening. I just get my information through them.

Participant: We depend on AARP a lot.

Participant: They have a good magazine they send you and they . . .

Participant: There's a lot of information that you don't get any place else.

Participant: Well, I got the similar information from United Seniors. They sent me a book probably about that size, which I would guess—I haven't seen that book—but I would guess it had similar information in it.

Moderator: Okay.

Participant: That describes what Medicare covers. And then they show me what the Medigap plans would cover. They've also advised me that I can contact different insurance companies about different Medigap plan?

Participant: They (AARP) are a profit making organization. They are going to be proprietary in their recommendations. Their pharmaceutical company for prescription filling, for instance, their Medigap policy, they're going to be leaning towards that. And there's plenty other good programs around.

Moderator: Can you detect what their bias is or what the partiality is towards certain programs or policy's or is it kind of regional?

Participant: All they advertise in their monthly mail-outs their pharmacy's so you know they're going to be bias. They have great big ads in there. I think don't they have a mail-in program and they also have a walk-up pharmacy here in the Washington area where you can walk up and get your prescriptions? And of course, they emphasize this. So naturally they're going to be a little bias toward their own place.

Participant: I was going to say that they are a pretty powerful organization. And there are a lot of things that they do that come to your attention that may not have to do with medical. But they can do a whole lot of things because they have a whole lot of power, like going to a hotel, for example. You can use them. There are a lot of things you can do with them that give you a lot of faith in them. So you have a tendency to believe when they tell you something about Medicare. You have a tendency to go on with what they say.

Moderator: Do you find the information you get from them to be useful information, good information, accurate?

Group: Accurate.

Group: They are pretty good.

Group: About once a month I get it out of the mail.

Group: I get a newspaper from them.

Participant: There's—in my case, I take—I'm retired too, like several others here. And I belong to two retired professional organizations. And their journals have information concerning it. And in the AARP you get—there's a lot of information that comes through them about Medicare and that. There's a world of information. It's just sometimes it's more than you're interested in or you can deal with.

Participant: Well, I had organizations, such as AARP. Actually, it's been more in the forum of the retired officer magazine that has given me a lot, because they've had a lot of coverage about subvention, which for those that are in the military, we're in an area that was selected to be a part of this where our Medicare would be paid to military facilities. So we could use military facilities after 65 freely, rather than on a space available basis.

Other Sources

Most of the important information sources identified by current beneficiaries are not yet known by or available to individuals about to enroll in Medicare. Several participants about to enroll mentioned employers as important information sources. Few participants mentioned health-related support groups they belonged to.

People About to Enroll Mentioned Support Groups and Employers as Information Sources

Participant: There are so many support groups that you could go to. I have sleep apnea, and there's a sleep apnea support group where people meet together and get information from the suppliers and physicians . . .

Participant: I have a support group, and you meet and you also get a newsletter.

Moderator: Which support group is that?

Participant: Prostate.

Participant: I'm just surprised that we are not talking about letting our management that we worked for these years, be responsible for giving us information. And let me just tell you, I'm a retired military man. And that personnel person in the Army that's responsible for that made sure I knew when I turned 65 I can forget going to these health places that the military operates, because Medicare—you've been paying that and now it's time for them to take over and take over the responsibility. Now I'm assuming that if you're working for any kind of an agency and you get ready to retire, somebody in personnel is supposed to tell you these things, before you retire. Now, if they don't, let me just tell you, if you got a mother-in-law at home and you go to a nursing home, they can tell you. They'll tell you anything you want to know and they'll take your money all at the same time, but they know that pretty well. And these health maintenance organizations know this information about Medicare too. And they will tell you as well, but I—your responsibility is really your personnel people.

Participant: I have an additional source of information that I've neglected to mention, because I hadn't thought of it. My former employer has been a source of a lot of information to me, because I worked for the same company for 35 years. Therefore, my coverage continues as a retiree. However, as of age 65 it changes. And they, at that point, assume whether I take Medicare or not, they assume that I take Medicare. And anything that Medicare would have paid, they don't pay. Anything that they would normally pay that Medicare declines to pay, they will pick up. I've learned, that's what they call a carve out.

Participant: I'm the same way. I'm retired Air Force. I get all the information from them, more than anything, and it comes to me every month.

5. INFORMATION MEDIA

This chapter describes participants' preferences for how they receive information. We gathered considerable information about media preferences from participants' descriptions of recent experiences seeking information about Medicare. In addition, both focus group protocols probed for detailed reactions to a few priority media, including the Medicare Handbook, toll-free telephone assistance, and automated response units (ARUs), and computers and the Internet. It is important to recall that discussion questions focusing on toll-free telephone assistance and ARU features evolved over the course of the focus group data collection. Thus, some participants reacted to relatively general questions about using the telephone and automated menus to obtain information, some participants reacted to more specific questions about features of telephone assistance systems that make them easier or harder to use, and some participants discussed their concerns and reactions to using the telephone and automated menus for a few concrete and specific purposes.

5.1 Major Findings for General Population Beneficiaries

Focus group participants from the general population of Medicare beneficiaries consistently said they wanted interactive communication with people who understand and know the answers to their questions.

Preferences for Interactive Communication
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"As far as I'm concerned as far as information from Medicare, there is nothing in the world like being able to get on the phone and get a one-on-one conversation with someone. You can explain what is the matter and they can give me the answer that I need to know without all the machines."

Medicare Handbook

Most participants from the general population recognized the Medicare Handbook, although there were groups where relatively few participants said they were familiar with the Handbook. Those who did recognize the Handbook said they generally use it as a reference. That is, they put it away without reading it, but referred to it when problems or questions arose. Almost all beneficiaries who used the Handbook agreed that it provided them with the information they needed in a clear and concise way.

The Medicare Handbook Used as a Reference
--

“Well, every time we have some question I get the book. That’s where the information is.”

Participants’ suggestions for improvement included adding an index, a glossary, a list of resource telephone numbers, and a list of EOMB procedure codes.

Radio and Television

Most participants rely on the media for some information, but they were very aware of the commercial interests that influence what is presented and how. Several participants expressed concerns that commercial interests and sensationalism characteristic of mass media sources can obscure the story.

Skepticism About Television and Radio
--

“I think most of the information is tainted... You’re not going to get what is made to be newsworthy... They are out there selling radio time, television time, they want to peak your interest. They give you half truths... You have to be very, very careful.”

Videotapes

Many participants from the general population had seen videotapes on health-related topics in their providers’ offices, or requested videotapes from their insurance companies. Although suspicion about the videos’ sponsors resurfaced in this discussion, reactions were for the most part positive.

Videotapes Are Accessible

“My doctor... he has the videos right in his office that are on his TV. The videos are played all the time. They are healthcare, all the information. Every time I come in I look to see if there’s something decent playing and it’s always something.”
--

Videos seem conducive to targeting specific information, and may be particularly useful for topics on which beneficiaries prefer or require more interactive communication.

Newspapers and Magazines

Newspapers and magazines were an important information source for the general beneficiary population, particularly for those who are active information seekers.

Newsletters and Magazines Are Sources for Proactive Information-Seekers

“Another source that I have found to be helpful to me is some of these medical newsletters that come out once a month... You can... get updated on certain diseases and treatments for them.”

Notices in the Mail

When asked, general population participants said they wanted information to come to them through the mail. However, they also confessed that they often don't read the mailed notices they already receive. *Mail notices with distinctive designs will enhance the likelihood that beneficiaries pay attention to them.*

Mailed Notices Are Unlikely to be Read

“I have a problem with mail particularly the last quarter of the year. For a lot of us it is about 96 1/2 percent junk mail.”

Moderator: “Do you get notices about health in the mail?”

Participant: “I don't read everything that comes. There's so much of everything.”

Computers and the Internet

In discussions of computers and the Internet as information sources, participants from the general population generally focused on the kind of information that would be available and ease of use rather than on the medium itself. For instance, quite a few participants were open to using computers for information retrieval, but they also expressed concern about the accuracy and timeliness of the information, their privacy, and the costs to the Medicare program. For the most part, participants would still rather get answers to their questions from a person. *Compared to current beneficiaries, future generations of Medicare beneficiaries will likely be more receptive to, and indeed may even expect, computer-based information from HCFA.*

Computers Are an Unfriendly Resource

“The more assistance you have like this, the fewer live people that you're going to have in the future to sit down and talk to. I'd rather sit across the desk and talk to someone, someone who knows the system and has the computer there to look up things. I would feel much more comfortable.”

800-Numbers and Automated Telephone Menus

Participants who use toll-free numbers to speak with a human generally had good things to say about 800-numbers. Some of these participants did complain about language barriers or poorly trained operators. Most participants disliked automated telephone menus. With probing, the general preference was for no more than two levels of menus with no more than three options each. Other suggestions from participants included: enforcing short waiting times (no more than 10 minutes); recordings that report how much longer the wait will be; an option to repeat menu choices; and the ability to ring an operator at some point during the automated message. In addition, menu options should be slowly and clearly enunciated, well-defined, and allow for easy classification of most information needs.

Strong Preference to Speak With Human Operator
“Medicare could set a precedent by... letting us talk to a human being or at least only one or two choices to get to a human being.”

5.2 Major Findings for African-American Beneficiaries

African-American participants' preferences were similar to those of participants from the general beneficiary population. In both groups, participants said they like to have information in a format that allows them to refer back to it as it is needed. Also, they want to be able to talk to a human when their questions are too specific for brochures or videos to address. Where the two populations diverge is in their use of and level of trust in particular information channels. African-American beneficiaries seemed more likely than those in the general population to rely on radio, television, and videos for information about health care. In addition, they were more enthusiastic about the idea of using computers. On the other hand, a greater proportion of African-American participants expressed a lack of trust in these sources and others, including the Medicare Handbook.

Medicare Handbook

Almost all African-American participants recognized the Handbook, although many said they have not looked at it. Those who had read the Handbook were most likely to have used it to address specific problems or questions.

Handbook Used to Address Specific Problems
“What I looked up for was to see if they were gonna pay for what I was having done.”
“I looked... for a resource for extenuating circumstances where it didn’t happen in the United States, what the procedure was.”
“If something comes up, I use it for a reference.”
“I just kept it so if I did have a problem I could find it.”
“I just look into it sometime, but I have no need to use it yet.”

Several beneficiaries agreed that the Medicare Handbook is clear and provides good information. As illustrated by the quotation below, at least one participant was suspicious about HCFA’s motives in publishing the Handbook. Another participant reported they did not receive the Handbook and seemed to attribute this oversight to HCFA’s preoccupation with bill-collecting. These comments are consistent with findings from the second Inventory Report that in some cases, elderly African-Americans need to be reassured of an information source’s trustworthiness.

Suspicious About the Purpose of Communications From HCFA
“The reason I haven’t had a chance to look through it is because... they have two sections of Medicare, A and B. And they’re always pushing for you to buy Section B. And you have to pay for that. That’s \$40 a month. All of them is pushing for that. Every agency out there.”
“I never get anything from that Health Finance Group, except requests to pay the money.”

Radio and Television

Among those participants who commented on radio and television media, the general attitude was somewhat negative. The second Inventory Report noted that mass media can be particularly ineffective communication vehicles for elderly African-Americans. For instance, older African-Americans may not respond to messages that are usually targeted to the majority population, or they may feel alienated by stereotypical images of minorities in the media.

Information From Radio and Television is Misleading

“Well, you have to be very selective and listen very carefully to information from TV and radio. They do give you the sources, you know, like sometimes you wonder where can I get this information from?”

“It’s misleading.”

“They do mislead you because they’ll say,...’everything was paid for me...all I have to do is pay five dollars for my prescription...”

The second Inventory Report also noted that African-Americans are more likely to be receptive to information communicated through radio programs oriented toward them than they are to other vehicles such as mass mailings. Focus group participants did not mention these programs as favored information sources. However in one focus group, many of the participants said they like to get their information from television programs, and even wished the presentation formats were longer.

Television is the Preferred Information Source for Some

Moderator: “...I’d like to... give you a chance to mention any other way that you think is important and how you can receive information on health care.”

Participant: “Television.”

Participant: “I’ll turn on the television.”

Moderator: “What is good about getting information on radio and television?”

Participant: “Up to date.”

Participant: “It’s free.”

Participant: “Well, whether it’s true or not, it’s handy.”

Participant: “I watch the Today Show a lot. And there’s a guy... who comes on periodically... with a program as to how to lose weight. That is the way to get across.”

Moderator: “So what’s not so good about radio and TV...?”

Participant: “What I find wrong with radio and television is that sometimes it’s too brief. The radio and television is time in units. If that guy who is talking can’t cram it into so many seconds, you’re not going to get much out of it.”

Videotapes

Several participants reported using videotapes to obtain information about health and medical issues. For the most part, participants seemed pleased with the information and the medium’s flexibility. One beneficiary even prefers getting health-related information through videos.

Advantages of Videotapes as Information Sources

Moderator: "Is there anything that's particularly good about getting information from a video?"

Participant: "Well, you can use it in your own place and time, and you have access to it so you can use it when you want it and you have the time to understand what they're talking about so I like that aspect."

Moderator: "Where would you like most to be able to get health information?"

Participant: "Video... Put it on a video and if you don't get it all at one time you can turn it on. You can always go back."

Participants expressed some suspicion about commercial interests of sources providing videotaped information.

Videotapes Are Too Commercial

Moderator: "Would you use a video?"

Participant: "No."

Moderator: "Why?"

Participant: "Because that's commercial."

Moderator: "Oh, you consider that a commercial?"

Participant: "Yeah, for sales."

Newspapers and Magazines

Many participants reported relying on newspapers and magazines for information. there were mixed attitudes about whether these sources should be trusted. Participants noted that newspapers and magazines don't always publish information that's true, and they may sensationalize disease rates among African-Americans.

Information in Newspapers and Magazines is Biased and May Be Untrue

Moderator: "[Are newspapers and magazines] a good source?"

Participant: "No."

Moderator: "Why not?"

Participant: "I don't want to have to sort out whether it's true or not."

"[In]... newspapers and magazines... every new disease comes out, blacks have it before anybody else."

Some participants preferred magazines to newspapers because they felt the former provides more in-depth information.

Magazines Provide In-depth Information

“I get the Christian Magazine, that has a whole lot of information. Fifty-Plus Magazine, that has a whole lot of good information. I haven’t seen anything negative about any of them. They give you a whole lot of information and it’s free.”

“I think magazines go into more detail, you know, like with medicine. They don’t sum up the medicine in newspapers, they just have little flashes.”

Notices in the Mail

African-American participants generally agreed that they prefer to receive information in the form of mailed written notices. Often, this was for the same reason they liked the Handbook—they can refer to written information as they need to. One participant reported preferring mailed notices because other people can read them for her.

Beneficiaries Save Mailed Notices and Refer to Them Later

Moderator: “What is the best way for me to answer those questions for you?”

Participant: “The mail.”

Participant: “Then you can refer to it and not have to tie up a whole morning on the phone.”

Moderator: “What kind of media would you prefer to get your information?”

Participant: “Written.”

Participant: “Yes.”

Participant: “Mail, written.”

Participant: “I prefer if it’s coming from an agency to have it in writing.”

Participant: “You have time to read it. You can go back and read it.”

Participant: “You can refer back to it if you want.”

Participant: “If you read it you understand it more than if it’s coming from your television.”

“I would like to have it at home so somebody could read it for you.”

Computers and the Internet

African-American participants were wary of using a computer. Their reasons included privacy, cost, and ease of use. Participants mentioned concerns about overall computer security, and several beneficiaries did not like the idea of going to a public place in order to access computerized information about their health or their Medicare accounts. This may be related to a finding from the second Inventory Report finding, that African-Americans are particularly likely to view their health as a private matter that is embarrassing or difficult to discuss even with health care professionals.

Concerns About Computer Security

Participant: "It's a nice toy, but they are dangerous."

Moderator: "Why are they dangerous?"

Participant: "Because, as she said, one wrong keystroke and everything is gone."

"How could you prevent it from spilling out or spilling over? How could you keep it from the hackers, and they are out there in great numbers?"

Concerns About Protecting Computer Users' Privacy

Moderator: "What about if you were on a computer and you just wanted information about your own personal claims?"

Participant: "That leaves the door open for other people to pick up information on you so your privacy is gone."

"Oh no, I don't want to go to no public place."

Moderator: "Another issue on the table is that you wouldn't necessarily access personal information in a public place?"

Participant: "No, I would not."

Participant: "No."

Participant: "No."

African-American participants expressed discomfort with the cost of implementing a system that allows them to access information about their Medicare claims over the Internet. They wondered whether seniors would be able or willing to learn to use computers.

Concerns About the Costs of a Computer System

Participant: "Would it reduce the overall cost of Medicare?"

Participant: "I doubt it."

Participant: "I doubt that, because first of all the average one of us would have to go into debt to get the computer."

"I don't know if that would be a good idea for Medicare because with all of the older people, a lot of them couldn't afford computers. It would be an expensive source."

Concerns About Seniors' Ability to Use Computers

"I wouldn't want to trust anything to me getting information off a computer."

"Well, I don't know enough about a computer. When I came up, you know, there was no computers. You know, I'm computer illiterate."

"Like she said, I'm illiterate to dot com."

"If they want to put one in a library or something like that, just for those few younger seniors who are more computer literate, then that might be fine. But for us to become sufficiently computer literate for the purpose of accessing data about Medicare, I think out of 100 people, 90 would not use it."

Despite these reservations, a small but noticeable number of participants wanted to try using computers for the purposes described, and some even pointed out the advantages of such a system.

Some Viewed Computers as a Good Source of Information

Moderator: "Let's say... you get access to computers in public places such as libraries, senior citizens and Medicare offices."

Participant: "That's great."

Participant: "Yeah, I'd do that."

Moderator: "Who would go into the Internet to get information?"

Participant: "I love the computer."

Moderator: "What would you get?"

Participant: "Well, probably I'd go in there looking for a doctor."

Moderator: "Okay. Would you get information about your own personal claim?"

Participant: "Yeah."

Participant: "I'd use the computer."

Moderator: "What kind of... health care information would you get?"

Participant: "I don't know, but if I wanted information, I'd try to use it."

Moderator: "Would you be willing to go on a computer to find out information about health care and health and Medicare?"

Participant: "Sure."

Moderator: "Is it enough to make you want to learn how to use the computer?"

Participant: "Oh, I'm pretty sure I could learn."

Computers Can Save time

"I would use it if I considered it necessary to be used as a time saving device, if I understood what I was doing."

Participant: "It's easier to punch one key on the computer than it is to read a book."

Participant: "That's right."

Participant: "Just use the table of contents."

Participant: "But it don't really explain it. When you get them bills, I've read how much they pay. But when I get my bills, I mean the last year I've been in the hospital twice and I've been getting those bills back. They pay so much of this and so much of that and when you go to the hospital you don't even know what you're going to have to pay. You don't know what you got to pay. And then once you get in there and they've got all these different, one gives you anesthesia, one comes in for this and one comes in for that and it don't explain all of those things."

Moderator: "Where would you like most to get your information?"

Participant: "I would say the computer because then I don't have to leave home."

800-Numbers and Automated Telephone Menus

Many African-American participants reported dissatisfaction with automated telephone systems. Few were willing to endure more than five menu options or more than one menu level. One participant reported a preference for mailing questions to the appropriate agency rather than using an 800-number. Several participants said they hang up when they hear an automated message. Others said they have learned to press the operator key.

Complaints About Automated Menus and Some Avoidance Tactics

Participant: "If you want this, punch that. If you want this, punch that."

Participant: "Oh, that's terrible."

Participant: "And they say if you don't have that, stay on the line and someone will help you so I stay on the line."

Participant: "And you stay on the line for an hour."

"I don't know, because I'll tell you, that punching drives me crazy."

"Actually, when I'm really interested in something, I prepare my letter with my questions and I make a copy and I send it... through the mail, registered, with the department's attention on the outside. And then when I hear from them, at least I'll hear from them. And I won't be on the phone for 20 minutes with 19 different things... There's a list of what I want to know and that very well may have to go to six different offices to be answered, but... it... will have an answer on them. When I get them back, it may be 90 days, but I've got it."

Moderator: "What do you do when you reach that kind of message where you might have to enter some more numbers to get where you want to go?"

Participant: "I hang up the phone."

Participant: "I put my finger right on operator."

Moderator: "Does the length of the list make a difference to you?"

Participant: "Yes, because the one you want is usually at the bottom."

Moderator: "How many numbers are too many numbers for you to look and see in terms of options?"

Participant: "I went to six. But I've learned to just put your hand to operator and it cuts it out right away and I learned that. That was getting on my nerves. So now when they say punch six for this, I push my hand up on operator and they say hold on, somebody will be with you in a moment. I've learned that."

Specific complaints about automated systems were similar to those mentioned in the general population focus groups: option lists are too long and categories provided do not match the caller's problem.

Automated Menus Are Too Long and Complicated

"Be prepared with a chair and a sandwich to sit there and wait and you punch in all these numbers... and you push the one for repeat because you forgot."

"And you have to listen through the whole menu because the topics aren't... you know what you want but you don't know how to classify what you want to ask into their menu. It's just not clear which one. You might need four or five but you'll listen to the whole thing and you're not going to know which one."

Participants reported that they are more tolerant of waiting on hold than they are of automated menus. Although several said they would wait no longer than eight minutes, others would remain on hold longer if the question or problem was extremely important, and some were willing to wait if a recording told them how long their wait would be.

Waiting On Hold Not a Problem if the Question is Important

<p>“It depends on what I called for and how important it is to me. If it’s important to me, I’ll wait until I get it.”</p>
--

<p>“This is very important. If it’s something that I really must do, yes, I’ll stay on the line. But it must be something that I must do.”</p>
--

Beneficiaries Want to Know How Long They Will Be On Hold

<p>“The better ones tell you your call will be answered in approximately two minutes or three minutes and we suggest you call back on another day. And that’s fine.”</p>
--

<p>“Social security has a good arrangement. If you call at certain times the 800-number and they will tell you how many minutes approximately before a representative will get to you. I think that’s good because it gives you an idea how long you’re going to be on the phone to get some help.”</p>

For the most part, participants agreed that they’d rather speak with a human, even if it meant waiting on the line a little longer. There was a small number of dissenters, however.

Most Prefer Waiting for a Real Person
--

<p>Participant: “I’d rather wait and then I’m talking to the person.”</p>

<p>Participant: “Yeah, I don’t want to talk to those numbers.”</p>
--

<p>Participant: “You know, I like to talk to people. Talk to me.”</p>

<p>“I don’t talk to machines.”</p>

<p>“Well, they’ll tell you punch in for this one, punch in for that one, punch in for this. Do you know what I mean? They have different options to punch in and then you wait for the one that you want to get so I might just want to sit there and wait for the operator to come on.”</p>
--

<p>“Sometimes you just want to talk to somebody, you want to hear a voice.”</p>

<p>“I’d prefer to punch it myself.”</p>

<p>“Well, I know before they got all these punches it was awful because they would say all of the operators are busy, can you hold on. You would hold on much longer than it takes, I think so.”</p>
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5.3 Major Findings for Hispanic Beneficiaries

The most obvious distinction between the information needs of general population and Hispanic beneficiaries lies in their preferences for the language used to convey that information. For most of the media discussed, Hispanic participants said they wanted Spanish-language options available. Hispanic seniors also seemed more likely to rely on and trust information from radio and television, less likely to watch videotapes on health topics, and less likely to be concerned about privacy issues surrounding computer use. At the same time, Hispanic participants were as likely as their general population counterparts to use the Medicare Handbook as a reference source, to prefer mailed written notices, and to avoid automated telephone systems.

Medicare Handbook

Most Hispanic participants recognized the Medicare Handbook, although in one Hispanic focus group nobody remembered it. As in the general population, Hispanic participants reported using the Handbook as a reference tool. For instance, some beneficiaries mentioned using it to find out whether medical procedures they needed were covered. Conversely, a few participants who said they never had trouble getting their bills paid reported that they do not use the Handbook at all.

Handbook is a Reference Tool for Many

Moderator: "What kind of information do you look up?"

Participant: "To see if something is covered."

Participant: "To see if something is covered."

Moderator: "Is there any other reason that you look in your Medicare book?"

Participant: "Where to call."

Participant: "Benefits. The benefits that they have, and the benefits that are not covered are in there."

"I refer to it once in a while... I'm interested in knowing exactly what my benefits are going to be. Generally before I go see the doctor, I'll go see, depending on what the problem might be. Then I have a pretty good idea of what's going to be covered by Medicare and what might be picked up by my supplemental insurance."

"I never even bothered to look at that, or the one that Blue Cross/Blue Shield [sent]... As long as they pay the bills, I could care less."

Language barriers were a problem for Spanish-speaking Hispanic participants who might benefit from information available in the Handbook. Most participants were unaware of a Spanish-language version of the Handbook. Some participants reported that they rely on family members or neighbors to help them translate HCFA letters or brochures that were in English. The length of the Handbook makes these requests difficult. According to the second Inventory Report, close to 40 percent of Hispanic senior citizens speak little or no English. *There, the availability of a Spanish-language version of the Medicare Handbook should be publicized more widely.*

English-Language Handbook Is Not Read

Participant: "...for example, I can give my daughter... the letter that I received and... she tells me, 'Okay, look, I'm at the office right now. I'll call you later and let you know.' But right now they're sending me [the Handbook]"

Moderator: "What do you mean?"

Participant: "I can't give that to my daughter to read. She doesn't have the time."

Moderator: "Do you remember, maybe, receiving it but perhaps because it was in English you might have not really paid attention?"

Participant: "I know I haven't received it because just seeing the name Medicare I would have paid attention to it. And who in the heck are you going to give that book so they can read it?"

Moderator: "So basically you wouldn't give it to anybody?"

Participant: "No, because they can read a page, a letter, but a whole book? Someone who is so busy?"

Moderator: "If you received this in Spanish... ?"

Participant: "Oh, it would be a lot better. Much better."

Moderator: "Have you read it?"

Participant: "Well, it's in English."

Moderator: "So then what do you do?"

Participant: "Well, I keep it in a drawer."

Feedback on the Handbook was positive among those who had reviewed the Handbook, either in English or translated into Spanish by a helper. Hispanic beneficiaries said they found the Handbook helpful and easy to understand.

The Handbook is Clear and Informative

“I still think that the main source of information, as far as I’m concerned, has been the yearly pamphlet that you’ll get from... Medicare. And it gives me everything I need to know in that pamphlet. And you get one every year. So that’s good enough information for me. I don’t need anything else.”

Participant: “My daughter is the one who interprets for me.”

Moderator: “And so it was in English, right?”

Participant: “It was in English, but she speaks Spanish. I don’t know how to speak English myself.”

Moderator: “Do you think once your daughter read it that it was clear to you?”

Participant: “Yes.”

Moderator: “Do each one of you feel that the booklet states everything clearly?”

Participant: “I think so.”

Participant: “Yeah.”

Participant: “It’s very informative.”

“I think this [the Handbook] is better information and it’s more direct.”

Radio and Television

A large number of Hispanic participants reported relying on television and radio for information. Unlike comments from the general population, there were few negative assessments of these media among the Hispanic participants who discussed them. This finding is consistent with findings from the second Inventory Report that Spanish-speaking seniors tend to prefer television and radio over print media such as magazines. Furthermore, the Inventory Report noted that many older Hispanics who were not born in the United States listened to the radio in their country of origin and continue to do so in their new homes.

Radio and Television Are Important Information Sources

Moderator: “What’s the best way to reach you... as far as media, television? I know you talked to me about radio...”

Participant: “And television’s important, too.”

Moderator: “So you say radio and television is most important.”

Participant: “Yes. There’s a commercial that they put on the radio for elderly people that are alone.”

“What is good about [television] maybe because it might be the latest thing on the market that can help whatever problem that you might have, or know somebody that has it. Usually... TV mostly, will give you the latest thing that’s been helping a particular problem, and so you pick that up.”

“TV comes up with some pretty good programs once in a while.”

“I don’t know how many people here have seen it, but last night there was a full hour on channel five... And I mean, that was a very good, informative program. And those are special shows that our local people here put out that are very informative.”

Videotapes

Among Hispanic beneficiaries who discussed videotapes, there were none who said they used this medium to get health-related information. This diverged from the experiences of general population participants, many of whom had seen videotapes on health topics. A few Hispanic beneficiaries were interested in using videotapes as another source of information.

Interest in Videotapes as Potential Information Source

Moderator: “How about videos? If this information about diabetes or prostate, if this were on video, would you go look for this video and watch it?”

Participant: “Yes, I would.”

Participant: “Yes.”

Participant: “I would like to get that information that way, yes.”

Newspapers and Magazines

There was very little discussion about newspapers and magazines in the Hispanic focus groups. A few participants reported that they use these media as information sources and that they like being able to refer back to them, but no one gave strong positive or negative opinions.

Advantages of Magazines as Information Sources

“But I think it’s cheaper. It’s easier to hold and they use information in the magazines. I always look at magazines.”

“I get information through Methodist, you know, Women’s Plus, from Santa Rosa. They send you tabloids and you get all kinds of information. And they have all kinds of meetings and all kinds of things going on that you can attempt.”

“You can always refer to the article if you have questions or if somebody asks you about it, then you can refer to the source, rather than, ‘Well, I heard this.’”

Notices in the Mail

Many Hispanic participants said that they prefer receiving information through the mail in the form of pamphlets and brochures. Of course, language barriers are important features of these information channels.

Mailed Information is Good, Mailed Information in Spanish is Better

“I have always done everything via mail, since my retirement.”

“The best thing they can do is send us information in pamphlets.”

Moderator: “Where and how would you like to receive this information? In what form?”

Participant: “Through the mail at home. That way we’ll keep the information.”

Participant: “Through the mail.”

Participant: “Through the mail and in Spanish.”

“To me, it should be in Spanish as well because if they send it to me in English, I’m not going to understand. To me, it should either be a letter, a telegram or some kind of notice. But right now, there are a lot of difficulties in wanting to read it.”

“For example, you know, maybe there’s a number that I can call and say, ‘Listen. I want all my papers in Spanish,’ because I’ve requested it before in Spanish and they started sending it to me in Spanish. And I want numbers in case I can call. And that’s the way it should be.”

Moderator: “So the problem with what you’re receiving through the mail has to do with language?”

Participant: “Yes. It should be in Spanish.”

Computers and the Internet

Some Hispanic participants responded positively to the idea of health care information being available through computers or the Internet, especially if someone is available to help them use the new technology.

If Instructions Are Provided, Computers Can Be a Useful Information Source

“I think it’s [the computer] the most wonderful thing to have if the person is capable.”

Moderator: “Perhaps you could use computers at the library?”

Participant: “I would like to do it, but I don’t know how to.”

Participant: “Oh, I would like to, yes.”

Participant: “Well, what we need is to have instruction in Spanish on how to use the buttons. That’s all we need.”

Participant: “Well, as long as the system is in English and in Spanish, then it’s fine.”

“We need programs for the senior to be able to learn.”

Moderator: “Do you think that they [a computer company] should give you information about supplementary plans?”

Participant: “Yes.”

Moderator: “And how about information about managed care plans?”

Participant: “Yes.”

Moderator: “And information about your own personal claims?”

Participant: “Yes.”

Moderator: “So there is no drawback of having this kind of information in a computer?”

Participant: “Well, if you don’t know how to use it, then your relative will and they’ll be able to teach you about how to use it.”

A greater number of Hispanic participants were skeptical that computers would be any better than current sources from which they get the same information. One participant noted that computerized information would be more helpful for doctors than for beneficiaries.

Current Information Sources Are Just as Good as Computers

Moderator: “What do you feel about information about supplements to your insurance plans?”

Participant: “There are so many plans I don’t think you could get that much information. You would be punching that computer all day... the way it is now, though, we get this open season booklet and we can read it.”

Moderator: “What about general instructions on how to file Medicare claims?”

Participant: “Not pertinent. My experience has been that doctors have always filed. I’ve never filed anything.”

Moderator: “What about general information about what’s covered and what Medicare pays?”

Participant: “Well, we get that, don’t we?”

Participant: “You get that in a booklet every year.”

Moderator: “So do you think that using the computers is a good way to get some of this kind of information, such as the supplemental insurance coverage?”

Participant: “I personally don’t believe so. I don’t believe it’s too much information.”

Participant: “It would probably be more helpful to the doctors than anybody else, if you go in there.”

In contrast to the general population, no Hispanic participants expressed concern about privacy issues or timeliness of information. Access was an issue.

Computers Need to Be Accessible to Seniors

Participant: “If the computer were sitting, like, at the mall, and then you would need somebody to go in there and help you.”

Participant: “Or take you there.”

Participant: “Transportation.”

Participant: “If you don’t have transportation to go there, there’s no way...”

800-Numbers and Automated Telephone Menus

Hispanic participants noted that Spanish-language options should be easily accessible for them to make effective use of telephone toll-free assistance. Otherwise, Hispanic beneficiaries’ experiences with 800-numbers mirrored those of the general population. Hispanic participants complained about lengthy menus that are read too fast. They said they would rather talk to a human than work through a menu, and they pointed out that 800-numbers are generally not user-friendly for the elderly. Most Hispanic participants said they would stay on hold for three to five minutes without speaking to an operator, and they didn’t want to listen to more than three menu options or two menu levels.

Automated Menus and 800-Number Operators Should Speak Spanish

“Well, I don’t know English. So now you can ask for someone to speak to you in Spanish and they’ll do it for you. And that service they have improved substantially. It’s just a matter of communicating. And you seem to find someone for you, sure. They’ll try.”

Moderator: “And what do you think about this when [it’s in] English? Do you feel very comfortable with...?”

Participant: “No, no, because you don’t understand a lot of times that you call.”

Moderator: “So would you stay on the line?”

Participant: “No. Sometimes you’ll stay on the phone and listen and sometimes... I’ll listen to wait to hear if I hear it in Spanish. First I hear the recording in English and then I wait to hear it in Spanish.”

Participant: “Well, it’s new. On the one hand, you’re going to need some English because since they speak to us in English and I don’t speak English. But if this 800-number were to have an operator and she were to give you the information you needed in Spanish, they are going to be able to talk directly to you in Spanish.”

Moderator: “Would you use it?”

Participant: “Yes.”

Automated Menus Are Frustrating and Unsuitable for Some Seniors

Moderator: “How many selections would you be willing to go through?”

Participant: “Three.”

Participant: “That’s a good number, three.”

Participant: “If I have to wait any longer, I’ve forgotten what I called for.”

“What I hate about this 800-number is you call and they say, ‘If you want such and such, dial one, such and such, dial 2.’ You have to go through the whole menu. And by the time you get to the last one, you forgot which number you’re supposed to press.”

“I feel frustrated because I want to speak to a person and not to a machine.”

Participant: “Well, you know, there’s some people that are pretty elderly. How can they just sit there [and respond to automated telephone menus]?”

Participant: “If a person is living there by herself or himself, and then you’re hard of hearing...”

Participant: “I don’t think it’s good for people that are sick.”

“I think one difficulty there is especially when you’re getting older, is that they have to be very clear about, because otherwise, you’re watching to see which one you’re going to select. And if you don’t hear that clear, it can pass you.”

Some Prefer Speaking to a Real Person

“Well, I got hold of a human on the telephone one day, and I was able to ask him about whether he would be able to talk to me, and he said, ‘Well, what you really should do is ask the information through the recording.’ And I said, ‘No, I would really prefer to talk to you.’”

“And if you stay long enough, you know, they say, ‘Just say on...’ You just don’t push any buttons. Eventually you’ll get somebody to talk to. That’s what I do. I just stay on.”

Moderator: “Do you prefer to talk to someone?”

Participant: “Sure.”

Participant: “Always.”

Participant: “Always.”

Moderator: “Is there any other ideas that you feel could improve... 800-numbers...?”

Participant: “They’re not having a person there. That is the biggest mistake they ever made.”

A small number of Hispanic participants were enthusiastic about 800-numbers, saying that they are easy to use and that their questions are usually answered. In addition, a few participants had specific praise for Medicare’s 800-number.

Some Have Praise for 800-Numbers

Moderator: “Now that you know that you can call an 800-number, what do you think of this?”

Participant: “Oh, I think it’s fantastic.”

Participant: “Fantastic.”

Moderator: “How do you feel about using the 1-800-number? Do you think that’s good?”

Participant: “Yes, very good.”

Participant: “Yeah. You usually get a quick response.”

Participant: “I always call Medicare direct...”

Participant: “Yeah, the 1-800-number.”

Participant: “It’s a 1-800-number directly. You can talk to them very easy. They’re very nice.”

Participant: “They’re very nice.”

Participant: “No problems.”

5.4 Major Findings for Dually Eligible Beneficiaries

Dually eligible beneficiaries' media preferences were similar to preferences within the general population, with a few exceptions. Dually eligible participants were more likely to find the Medicare Handbook difficult to understand; they were more likely to rely on radio and television but less likely to rely on videotapes for information; and, when discussing automated telephone systems, dually eligible participants were less likely to insist on human contact.

Medicare Handbook

Almost all of the dually eligible participants had heard of the Medicare Handbook and had a copy of it. Those who reported using it said they used it mostly for reference. Some participants said they did not bother reading the Handbook at all because they weren't sick or didn't have a problem.

Handbook Not Often Read

"If you're not sick, you're not going to look it up."

"I keep it handy."

"I didn't really read it. I flipped through pages."

Most dually eligible participants agreed that the Handbook is clear and understandable, although at least one participant its organization. The Inventory Report recommended that HCFA materials directed toward dually eligible participants be presented clearly, using simple language and sentence structure, since this population's average level of education is lower than that of the general population.

Handbook's Organization Clear to Some, Complicated to Others

Moderator: "Do you find it pretty easy to understand?"

Participant: "It's not too hard."

Participant: "I have to read every word."

Participant: "If you have an easy problem, it's easy to find an answer. Nothing complicated."

"In the beginning I think they started off explaining the parts and then they... break that first subject up to say, 'continued on page 12,' or something like that... It's sort of a mishmash arrangement in there... I think when they made the book they failed to remember that a lot of these people that are going to be reading, or are trying to understand it, aren't that coordinated to go to 12 or whatever. I know we have a lot in our building that don't read and understand that it's extended to another place."

Radio and Television

Dually-eligible participants had diverse reactions to radio and television as information media. Several participants said that they watch television programs and call-in shows regularly. Others expressed reservations about the applicability of and motives behind information presented on television.

Televised Call-In Shows About Health Were Popular
Participant: "I noticed for the last three months after the news they tell you what they're going to talk about tonight, on your heart or on your eyes or whatever."
Participant: "I have one that says ask the nurse."
Participant: "Yes, they do. You can call."
Participant: "You can call and they give you information."
Some Were Skeptical of Television Show Sponsors' Motives
Participant: "I think radio and television had something in mind when they... they're trying to sell you their ideas. The fact that they're airing this particular thing is not necessarily for my benefit. It's more... for their kind of thing."
Participant: "It's a trust factor with me."
Participant: "Yes, I agree with you. I don't [know] whether I should trust that information."
Participant: "I don't think that one situation fits another person. What they sell to him might be perfect for him, but what they're advertising for him might not fit me at all, in any way, shape, or form."

Videotapes

Several dually eligible participants had seen videotapes in providers' offices or the library, but few had used them of their own accord. A few noted that they can not afford a VCR with which to watch videotapes. Dually eligible participants did not express strong reactions to getting information from videotapes—neither strongly positive nor strongly negative. For the most part, videotapes do not appear to be a medium that this population actively seeks.

Videos Are a Good Source of Information, But Aren't Always Affordable

"Sometimes you can see them in other places, in the doctor's office."

Participant: "[M]y physician gave me a video so that I could understand the medication that I am on."

Participant: "That sounds pretty helpful."

"Several doctors' offices have videos going all the time. I have been in some where they... it's with their specialty. And it's interesting. A lot better than what they put on the TV. So it is interesting to watch."

Moderator: "Has [videos] been a source of information for anybody here?"

Participant: "I can't afford a VCR."

Participant: "I can't afford a VCR either, but I want one."

Written Materials Provide Better Information Than Videos

"The video goes... with all the television we watch and everything, it goes in one ear and out the other real quick... [Y]ou don't retain it as well as when you have a pamphlet and you've read the pamphlet. And you say, 'That goes in with my health care envelope.' So when you need something, you go there, and there's the pamphlet. And it's black and white. Take your time and read it. But the video... [I]t's not a part of my life. A piece of paper is more my life."

"Several doctors' offices have videos going all the time... but I would not go out of my way to get a copy."

Newspapers and Magazines

A few dually eligible participants said they read magazines and newspapers for health-related information, and some liked them because they can use other sources to check the stories. As with participants from the general population, these media appear to be a source for active information-seekers.

Magazines Provide Pertinent Information

"I get Going Bonkers. It's a magazine. It's delightful... It is more oriented to psychology, but it does have a lot of medical information. There again, information, places that you can... they give a little bit of a blurb, a story. And then you can check it up. And the newspaper does the same thing. They have a health page and a science page. I read those carefully. And if something is of interest to me, there are places to verify or disqualify what is being said there. I do not take that word exactly, until I check it out."

Participant: "Well, I go back to this AARP magazine. It has all the information that I need. And, by virtue of the fact that they formed this magazine for people my age, things that would interest people my age. I would think it would behoove them to have the necessary information for people my age. And so far, I think they have."

Participant: "I thought it would be political... The last year it has gotten very political and distasteful."

Notices in the Mail

Although mailed notices were not directly addressed in any of the dually eligible focus groups, in the course of discussions on other subjects participants often brought up their preference for written materials. Although this population may be more likely to get information from face-to-face interactions or television programs, the second Inventory Report noted that a substantial number of dually eligible beneficiaries rely on written materials.

Preference for Written Materials

Moderator: “All the different sources that we talked about, where would you most like to...”

Participant: “My main thing would be in writing.”

Participant: “Leaflets like that or pamphlets.”

Participant: “I do read a lot. I read a lot. And that’s the only way it will stay there.”

Computers and the Internet

There was not a great deal of excitement for computers among dually eligible participants. While some were eager to learn how to use the Internet as an information source, others were less enthused. As in the general population focus groups, some dually eligible participants were concerned about access, ease of use, and privacy.

Enthusiasm for Learning to Use Computers

“I think that’s very interesting... I would love to learn it.”

“Computers don’t scare me... You can rely on the computer.”

Moderator: “So what would you think about... being able to go to a computer say in a library to look up information about how Medicare works?”

Participant: “Sure.”

Participant: “You say going to the library. It would be so helpful.”

Participant: “For some people that can do it, it’s terrific.”

Computers Not an Option for Those With Low Literacy

“There’s 100 million... people out there that have not even finished school. They didn’t even go to school at all. If they can’t use a typewriter, how in the heck are they going to use a computer?... Do you think a person like my mother, which is 70 years old, would walk to a library? I don’t ever think she’s been to a library in her life. I mean, there are a lot of people like that... [T]here’s hundreds of millions of people out there that some of them didn’t even go to school. So this is not going to help those people.”

Privacy and Accessibility Are Concerns

Moderator: “Suppose there was a computer available to use at a senior center or a library and there was some easy way for you to use it, would that be helpful to you?”

Participant: “If they keep it in repair, that’s fine.”

Participant: “Ease with which you could get to the computers would be important.”

Moderator: “Is there any problem with that?”

Participant: “Accessibility to computers.”

“Somebody knows your code or whatever it is they could find out your medical conditions. I think privacy would be [a concern].”

800-Numbers and Automated Telephone Menus

Dually eligible beneficiaries identified concerns about automated telephone systems that were similar to those raised by participants from the general beneficiary population. In general, dually eligible participants disliked the systems, especially if their questions were not answered satisfactorily. Participants were frustrated with long waits and with menus that don’t cover their questions, are too long, or are recited too quickly.

In contrast to the general population, few dually eligible participants expressed strong preferences for talking to a human. One participant said they wouldn’t mind automated systems if problems with waiting, response options, and option presentation were addressed.

Dually eligible participants generally concurred that waiting times should be no more than five or ten minutes. They also agreed that manageable systems should include one menu level with three to five choices.

Frustrations With Automated Menus and 800-Numbers

“You wait and wait and wait, and then you get somebody who doesn’t know what he’s talking about at the other end, finally. And that can be very frustrating. And you think, oh thank heavens I didn’t pay for that call.”

“Sometimes they hold you on for so long, forget it.”

Moderator: “What’s the most frustrating part of it?”

Participant: “When you have to hold on so long.”

“They never seem to have the information that you want on there. You’re waiting for them to say something and you’re calling for something like how to fix a broken leg and you get 45 different things, none of which have to do with what you’re calling about.”

“If you get on the phone and they ask you, you know the questions about what do you want, and you tell them. Well, to get that information you got to push number two. You push number 2, you sit there, you sit, you sit, and... you want to talk to this person or that person, ‘well you got to... push number three’... ‘Well, she’s not in. Can I help you?’ Well, you tell them what you want. ‘Oh, well then, you got to talk to this person. Push number eight.’ They make you go on and on for five minutes or so. By the time you get done, you don’t even know what you called them for.”

“Well, anybody, let’s say over 60 or 65, or let’s say 70. I mean, we don’t understand... we’re getting to an age of Alzheimer’s disease and all of this. And then they tell you, well, you have to press this number and then answer from there. You press this other one, and who do you want to talk to and blah, blah and all this. And by the time that went all through there, you don’t know who in the heck you want, you know. You forget.”

“Sometimes they speak so fast you don’t have enough time to digest what they are saying and you push the wrong button.”

Participant 1: “My problem. I’m on the phone. Now they tell me press 1, 2, 3. And then I bring the phone down to press the thing, now, see we’re not communicating anymore.

Participant 2: “Right.”

Participant 1: “When I get back up, they’re talking about something else. They lost me.”

Participant 2: “Because I, like you, have a princess phone. When you take—you have to have the phone in your hand to push those things. And by the time you got it up there, they’re on another subject. You’re right.”

“There’s a way around it, and I have learned it. I learned the hard way to get around it. They say, if you have a rotary phone please stay on the line. I don’t even bother with the menu any more. And pretty soon I’ve got somebody there.”

5.5 Major Findings for Rural Beneficiaries

Rural beneficiaries' preferred written materials and face-to-face interactions with people who can answer their Medicare- and healthcare-related questions. Rural participants emphasized that talking in-person to someone knowledgeable gives them an opportunity to assess their trustworthiness. Brochures and pamphlets permit self-paced review and reference. Despite general enthusiasm for written materials, some rural beneficiaries reported difficulty understanding information presented in this format.

Medicare Handbook

Relatively few rural participants remembered receiving the Medicare Handbook. Those who said they had a copy reported using it to look up questions about what medical procedures are covered or whether to choose an HMO. Some participants reported that they read through the entire book when they first enrolled in Medicare.

Handbook Provides Useful Information
"The way I use it, I look up what I needed to know."
"When I first got it, I remember that. I didn't throw it out. I put it in a drawer with my insurance policies and all."
"Well, when I first went on Medicare I read most of it."
"I checked them out when I bought my new teeth... I tried to find it in the Handbook."
"I looked in it to find out what advantage there may be in joining an HMO compared to the fee-for-service."

Rural participants generally agreed that the Handbook is easy to understand. A few had complaints about its language and organization. Indeed, the Medicare Current Beneficiary Survey found that rural beneficiaries do not rate the Handbook as highly as urban beneficiaries do. This is consistent with findings in the second Inventory Report indicating that seniors living in rural areas often have trouble understanding basic information about Medicare.

Handbook Sometimes Difficult to Understand

“It wasn’t complicated, but it was too repetitive. They used 14 pages to say what they could have in four.”

“I think there are things there that, even though they think they’re making them plain and understandable, there are still things in there that I don’t read because I really don’t understand what—if it’s applying to me.”

“And then I have somebody else look it up for me to figure out what I’m supposed to get... If I couldn’t figure it out, I would ask [my friend] to help me.”

Radio and Television

A few rural participants reported watching television programs about medical issues. Most complained about radio and television, but not always for the same reasons raised by general population beneficiaries. General population participants were suspicious of commercial interests and sensationalism. Rural participants were more concerned about not being able to refer back to information they hear on television. Rural participants also reported that televised information is often too general for them to apply to their specific situations.

Television and Radio are Informative

“There used to be a doctor on television some years ago... he has his own practice but he was on the TV. And then he put out a book here sometime ago. And I bought the book and it was very informative. And I think it’s very reliable information.”

“Well, I’ve seen a cataract operation on PBS, and a heart bypass operation... that’s good information.”

“I get some of my information from a local radio station in Chicago.”

Television is Not a Good Reference Source

“I think the newspaper is better because you read it and you retain it more than you do the television.”

Participant: “I’d rather read it, because a lot of times you’re not paying attention to the television. It comes on. You catch half of it. You get a misinterpretation of what the person is really saying. I think you need it in black and white.”

Participant: “Then you can go back the paragraph before...”

“The printed word is better for me. Because I don’t get it all at the first reading I can go back and check... With the TV and whatnot, it’s gone and I can’t...”

Television is Too General

“Well, when they do that, they’re putting it out wholesale. I would rather have where you can call somebody that’s supposed to know what they’re doing and talk to them, because these persons I feel I call and have some different things... I feel like, to me, everybody has different things. And when something different comes up, they want to know about it and they’d like to know where we can call and find out these things.”

Videotapes

There was very little discussion about videotapes in rural focus groups. Few rural participants reported personal experiences with videotapes as sources of information about health care. A small number of participants criticized videotapes as a medium, mentioning timeliness and cost, among other things.

Videotapes are Costly, Untimely and Boring

“By the time they were made and distributed they probably wouldn’t be of much value.”

“I’ll tell you there’s a lot of old people that probably don’t have video, can’t afford it. They’d get no information.”

“They [videos] are the most boring things in the world, people sitting around talking about their ailments.”

Newspapers and Magazines

There was little discussion about newspapers and magazines in the rural focus groups. Rural participants who reported using these media preferred magazines because the articles are detailed and the sources can be checked.

Magazines Contain Useful Information

“I use the national magazines, such as Newsweek and US News. I only, when I read something, I read it for knowledge sake to have an awareness of what is available and what, if I need to do something, what can I do to follow up. Get into more specifics.”

“I also get the Harvard newsletter. But I’m not sure that I couldn’t find the same information in magazines. It’s more detailed and interesting.”

“The AARP puts out Modern Maturity and it’s got nice articles in there.”

Notices in the Mail

Rural focus group participants expressed irritation with mailed notices. Participants reported receiving large amounts of junk mail, and many said they often throw mail notices out without even looking at them. Rural beneficiaries generally prefer information in writing. Apparently the mail is not the best way to get written materials to rural beneficiaries. *If information is mailed, the sender agency should be clearly visible on the outer envelope.*

Irritating Junk Mail Is Thrown Out With Barely a Glance

Moderator: "Like let's say notices in the mail. Do you like that?"

Participant: "No, not particularly."

Participant: "Well, they're out to make money, make a buck. They don't care. I don't think they care about you. They just care about selling their product. I think they're very impersonal."

"Oh, that garbage. It goes in the trash just as fast as I see where it comes from."

"One of the problems with getting this stuff in the mail is... we open our mailboxes and we have to stand there and throw this away, throw that away, because it's 90 percent junk mail. And you may be throwing away something, if you don't take the time to sit down and look at every single thing."

Important Mail Should Stand Out From Junk Mail

Moderator: "So it would have to be sent in a way that would..."

Participant: "...alert you... The Social Security Administration, most time people get something from the Social Security Administration..."

Participant: "...and you take notice."

Computers and the Internet

Rural participants reported mildly negative attitudes towards computers as an information source. Few endorsed the idea wholeheartedly. Instead, participants raised concerns about security and timeliness of computerized information. In addition, one respondent reacted against computers as being too impersonal.

Little Interest in Computers

Moderator: "The Healthcare Financing Administration is thinking about helping you to get access to computers in public places... Do you think you'd be interested in getting information... by computer?"

Participant: "That would not be wise at all... I wouldn't get in my car to go to a library or to a place to get computer information."

"Well, my own feeling is that for my informational needs, I could have done just as well with the old style card index in the library and do the searching myself in the stacks."

Computers Lack Security

“These whiz kids that can break in and feed wrong information, I would take the information I’d get and recheck it at the library.”

Participant: “They make mistakes.”

Participant: “Yes, they do make mistakes. Push the wrong button, they fried what you got... Push 00 instead of 01, and I have to pay my \$95 worth of prescriptions instead of six dollars. One little button.”

Participant: “Yes, that would be one drawback, I think. Now anyone could break into it, there’s no real security. It’s a tough one.”

Participant: “My first thought is that is sounded good, but then the issue of security and now it looks like a lemon.”

A few rural participants thought computers could be useful for some specific purposes, such as for reviewing medical bills or comparing supplemental insurers.

Some Favor Using Computers

“With a computer, yes, if it were there, I would find someone to tell me how to use it and get information out of there.”

“This is much less expensive than people staffed and sitting at a board and if you dial the right number you get to them eventually and then they say, ‘Gee, I don’t know the answer to that question.’”

Potential Uses for Computers

Moderator: “How about information about supplemental insurance?”

Participant: “This definitely would be helpful, absolutely.”

Participant: “As long as these were made factual and not based upon the PR by the supplemental people.”

Participant: “I’d like to have some ways or means to check on the people that’s giving out and doing the charge and make sure they do what they say they do, they put all this excess charge.”

Participant: “Is there any way that the patient would have to okay the bill?”

Computer-Generated Information is Impersonal and Outdated

“I feel that when they get into an area like that, the more they push a situation like that, the more impersonal everything becomes...”

“I wonder how personal they could answer my questions about something.”

“If it’s health or medical information, the real problem is, how recent is it? If they don’t update the computer records, it doesn’t matter how efficient the computer is. The information is old and outdated.”

800-Numbers and Automated Telephone Menus

Many rural beneficiaries were vocal in their dislike of automated telephone systems. Complaints centered around the length of menus, and confusing or unclear choices that don't pertain to their problems. Rural Participants differed from participants from the general population in a few ways. Rural beneficiaries expressed less concern about long waiting times. Rural participants also focused on accuracy more than promptness of response.

Automated Menus Cause Frustration

"I think those that invented that were young people. They forgot that they will get old some day."

Participant: "You have to listen to all these things to get through to the one you want. It might be item seven."

Participant: "It also may not be any of them."

Participant: "Yes, that's right."

Participant: "Then I try to get to the president and when they sound me off, I tell them your message don't make any sense as to what I want, you tell me where I'm supposed to go."

"But it isn't the money, it's the frustration. First they give you a series of numbers, then you get that, then they give you another series of numbers. Then another series of numbers and by this time, the tears are coming out of your eyes and I've taken a strong drink again."

Participant: "And you'll listen and it's—maybe you're not really thinking like they are because you don't know which button to push to get exactly what you want. And they've done one through ten of them and the only thing you can do is hang up and dial again. And you just do all that again. And you think, 'Which one was it I was going to talk with?'"

Participant: "By that time your blood pressure has gone up."

Waiting On Hold is No Problem if the Call is Important

Moderator: "How long would you wait?"

Participant: "How desperate are we to get in touch with someone?"

Moderator: "So if it's important enough to you, you'll wait."

Participant: "You want an answer."

Rural participants agreed that waits of five to ten minutes were their limit. They also favored three to five options each on up to three levels.

One Tactic for Avoiding Automated Menus

"If you have a rotary phone number they tell you to wait and mine is touch-tone but I still wait."

Some rural participants raised the issue of cost, both for HCFA and its customers.

Cost Considerations for 800-Numbers
<p>“I appreciate the fact that we have 800-numbers, yes. That has saved us quite a bit of money. They are very beneficial.”</p> <p>“It [800-numbers] works really well if you are old people. You can’t afford it if it’s long distance. You can’t stay half an hour on the telephone.”</p> <p>“I don’t... see how they can be cost effective. I really don’t.”</p>

Like most other beneficiary subpopulations, rural participants prefer talking to a person rather than using an automated system. In a few cases, rural participants said they would rather ask their questions face-to-face than over the telephone. The second Inventory Report cited research revealing that rural residents are particularly likely to seek interpersonal contact when they need information.

Preference for In-Person Contact
<p>“I dialed this morning. I got the 800-number, the first thing that comes on is ‘we do not have any record of your account.’ I didn’t reject anyone yet, I just dialed into the 800 number. I said, ‘What the hell is the matter with your computer this morning?’ But see this is again the frustration of not talking to an actual person.”</p> <p>Participant: “Whatever happened to the human beings?”</p> <p>Participant: “The only thing that can make it better is a living, human being.”</p> <p>Moderator: “What about talking to people on the telephone? Is that helpful?”</p> <p>Participant: “No, I don’t think so. I’d rather be face-to-face with a person.”</p> <p>Participant: “I’m particular about what I say on the telephone.”</p> <p>Participant: “Sometimes you really don’t know who you’re talking to.”</p> <p>Participant: “I’d sooner talk to, you know, a face.”</p> <p>Participant: “Yes. You can see who you’re talking to.”</p>

5.6 Major Findings for 64-Year-Olds About to Enroll in Medicare

Participants about to enroll in Medicare were most enthusiastic about person-to-person communication media. This was particularly true for participants who need help deciphering information they received in other formats, and for participants looking for answers to questions they felt were specific to their individual situations.

Pre-Enrollees Prefer In-Person Information

“If Medicare sent me a brochure and said come on over to the hotel tomorrow, we’re going to have a seminar, I’d jump on that... Because they would be right there and I could ask them and I would have the right questions to ask, too.”

Moderator: “It’s easier to get a grasp if you are talking to a person.”

Participant: “Yes, anything that you buy, like a VCR, if someone shows you. Even small groups, you can bounce it back and forth.”

Participant: “HCFA, or whatever. If they went to a place where quarterly you might go to an auditorium and somebody would give a presentation.”

Moderator: “Something in person.”

Participant: “Or you could go through and explain the things that most people have problems with and how you solve that kind of problem.”

Participant: “But maybe an hour presentation or something like that and a place where you could pick up the key bits and pieces and additional that you might need.”

Moderator: “[Y]ou mentioned in-person meetings. And I’m wondering what the rest of you think about a meeting in-person. Would that be helpful?”

Participant: “Yes. I think, you know, an informational meeting where they could point out what are these supplemental plans, and what has the government said that this is what the supplemental plan has to consist of.”

Participant: “I would like to suggest, like [he] suggested, perhaps if HCFA had seminars and invited those genuinely interested in them to come and ask all kinds of questions. It would be very helpful, but even more helpful would be for them to explain exactly how it works...”

Medicare Handbook

Relatively few of the participants about to enroll in Medicare said they received the Medicare Handbook. Most participants who had a copy said they sought it out for themselves.

Handbook is Actively Sought by Pre-Enrollees

“The one I have is a 1993 version... [w]hich I picked up at Blue Cross/Blue Shield.”

“My secondary insurance sent me that. I’m just getting started, you see, so they’ve been sending me all kinds of things, but that’s one of the documents they sent me. I don’t know where they got it.”

“When I called the Social Security Administration and posed my question, they sent me a raft of material. That was one of the pieces, as I recall.”

“Now it looks familiar to me and you know why? I got it in the trash room where I live. It looked interesting and I said I am going to take that. That’s where I found it.”

A few pre-enrollees who had not yet received a Handbook felt it would be particularly helpful if it is sent early in the enrollment process, perhaps when one reaches 64 years of age. *HCFA would be serving beneficiaries about to enroll in Medicare well by mailing the Medicare Handbook earlier than other enrollment materials.*

Pre-Enrollees Want the Handbook Earlier
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“It should be sent out at age 64 so that you can prepare yourself.”

“If you sent it out at the age of 62...”
--

According to the second Inventory Report, a pressing issue for beneficiaries about to enroll in Medicare is choosing the Medicare options that will be most appropriate for their needs. In describing how they’ve used the Handbook, some participants confirmed this assertion.

Handbook Used to Choose Appropriate Insurance Plan

“I’ve been collecting the information. I’ve got to make a decision whether to go with an HMO or do supplemental and straight Medicare. And it’s a hard decision... And so I guess I’ve been kind of putting off looking at them. I don’t want to look at it [the Medicare Handbook] yet. And yet I really need to.”

Participants who reported using the Handbook to answer questions generally reported that it was helpful and easy to use. In addition, participants said they were more likely to use the Handbook as a reference when questions or problems arose than they were to read it straight through.

Radio and Television

Among those participants who discussed radio and television, no one voiced the skepticism apparent in the general population. In fact, one participant pointed out the utility of television shows that present more than one opinion.

Advantage of Information from Television

“Well... where you have two guys speak on the television and one takes one position and the other takes another position... It’s a plus... that you get two different viewpoints rather than only one answer.”
--

Videotapes

Participants about to enroll in Medicare reported that videotapes can be effective for presenting specific information. A few participants reported they had received or seen videotapes provided by their doctors and were pleased with them. Others questioned the commercial motives of the distributors, as well as the timeliness of information presented on videotapes.

Videos Are Expensive and Untimely

“I’m going back as to the motivation for having these available. If the medical societies or the pharmaceutical companies think that these things are meritorious, they can certainly make it available for a heck of a sec less than \$20 a pop. Twenty dollars isn’t a lot of money, but it’s a lot of money for a video.”

“I would want to know when was it published? You put these things on the table and that thing gets old. Things change all the time.”

Notices in the Mail

Participants about to enroll in Medicare said they prefer receiving information in writing and through the mail. In part, this is for the same reason they like the Medicare Handbook—the mail notices get archived and referred to as needed.

Preference for Mailed Information

Moderator: “What way do you want to get information?”

Participant: “In the mail.”

Participant: “Through the mail.”

Moderator: “So you really prefer it in writing?”

Participant: “Yes.”

Mailed Notices Are Saved and Used Later

“Well, I’ve been collecting them... I’ve put them all together and I’m waiting for several more that I’ve called for to come in and I want to go over them all at one time.”

“You get a lot of information... I got a stack of mail that I haven’t had time to even read it, but the reason I kept it is because I want to go through it.”

Computers and the Internet

Participants about to enroll in Medicare had mixed reactions to the idea of using computers or the Internet to access information about health care and/or Medicare. Some were amenable to using the Internet as another source of information. Others were skeptical that computers would be widely used by current and soon-to-be Medicare beneficiaries. Participants thought that younger generations of beneficiaries will be more prepared to use computers and the Internet.

Some Positive Reaction to Computers

“I think it would be wonderful for those who have computers and have access to them. It’s another source.”

“It’s really a great source on the Internet...”

Skepticism that Today’s Seniors Will Be Interested in Computers

Moderator: “How about computers? Do you think that would be something that would appeal to you?”

Participant: “Probably for the next generation.”

Participant: “People resist change.”

800-Numbers and Automated Telephone Menus

Participants about to enroll in Medicare who used 800-numbers and were able to speak with a human seemed satisfied with their experiences, although a few participants complained about poorly trained operators. Participants mentioned another source of frustration when automated options do not seem to fit their information needs.

Satisfactory Experiences with 800-Number Operators

“You can ask a specific question rather than a narrative that may talk generally about what you’re concerned with but doesn’t answer specifically the question that you have in your mind. With the 800-number, of course, you can do that because you are face-to-face with them.”

Participant: “United Seniors has... an 800-number.”

Moderator: “They’ve been helpful then?”

Participant: “They have. They have consultants to answer questions about health care and Medicare, Medigap.”

Moderator: “What do you think about calling an 800, toll free number?”

Participant: “Only if we speak to humans.”

Frustration With Poorly Trained Operators

“Sometimes you get a person that don’t know anything about it, but he’s going to fill in, you know. He’ll just tell you anything. So you don’t get the right information.”

Menu Options Aren’t Always Appropriate

“One of the things I’ve had wrong... where you had to push, you know numbers. I don’t always understand what they mean by the subject that they broadcast, those choices that I have. And sometimes they don’t have a choice if it’s anything that I’m thinking about.”

“There should be one there where if nothing fits, give me a human.”

When asked about length of menu options and on-hold waiting periods, participants seemed willing to tolerate more of each, relative to the general population. This may be in part because participants are younger than the general beneficiary population participants, many of whom cited physical limitations brought on by age as barriers to a smooth interface with telephone automation. Furthermore, the second Inventory Report noted that those 50 to 64 are more technologically sophisticated than older generations, implying a higher level of comfort with automated telephone systems. General population participants usually set a limit at two menu levels with no more than three options each, and a maximum waiting time of 10 minutes. Pre-enrollees were willing to listen to five menu options and wait for 15 minutes.

One group of participants about to enroll in Medicare reacted to specific scenarios. A few participants who had used this kind of number were enthusiastic.

Positive Experiences With Fully Automated 800-Numbers

Participant: “Well, I’ve used it to get prescriptions... through Blue Cross/Blue Shield... And I just punch in the prescription number and everything.”

Moderator: “And never talked to a human being.”

Participant: “Never talked to anything.”

Moderator: “And it was fine.”

Participant: “Right.”

“I use this type of system maybe monthly, maybe more often, just checking my bank account. I’ll check in the deposits and things like that. It works like a charm.”

“I have also called computer companies where I had a problem and I’ve punched in the codes and got back something and tried it, and it worked.”

Several participants thought the idea of receiving standard information by calling and giving their names and addresses was a good idea, although a few expressed reservations about the security of the system. One participant pointed out that this may not be an issue when a beneficiary initiates the call.

Some Interest In, and Some Concerns About, a Fully Automated Medicare 800-Number

Moderator: "How would you feel about that use of a menu-driven system? And then automatically it send you a handbook."

Participant: "It's a good idea. I've done that before and I liked it."

"Sometimes they want your social security and everything else. They don't need my social security... Because if you give social security, you got our driver's license number. Anybody can use, you know. That's for me. I don't know about everybody else. They say, 'What's your driver's license number?' I say, 'What's that got to do with this?' 'Okay, then. Give me your social security number.' I say, 'You already go my phone number. Why do you want the rest?'"

"You initiated the call. You're initiating it. It's not somebody calling you. So there should be no qualms about giving out information that they probably already have anyway. And they just need to match it up."

When it was explained to the group that the purpose of providing these types of menus is to save money, several participants were more positive toward automated menus. *This reaction suggests that any introduction of such an automated telephone system should be accompanied by promotions that emphasize its cost-saving nature.*

Cost-Saving is a Good Reason to Introduce Fully Automated Menus

"See, I would rather they save money like that with... a computer answering your questions and giving the data and mailing you out the various information you need than to cut back on the services I want, like going to the doctor or something like that. If I had a choice as to where my money was going, I would prefer to have less personal contact on that end than having my benefits cut, you know, how much they're going to pay the doctor, or what's covered or premiums or et cetera. If they can save money that way, fine. I'm all for that."

6. Summary of Findings by Subpopulation

This chapter summarizes major results from focus group research activities, separately for each study population. Our focus group research was designed to answer two general questions:

- What information do beneficiaries want and need from HCFA?
- How can that information be most effectively made available?

We will use these two questions to structure the summaries in this chapter.

6.1 African-American Beneficiaries

What information do African-American beneficiaries want and need from HCFA?

- African-American beneficiaries need general information about the components of the Medicare program, including information about the purposes of Medicare Parts A and B; whether and why beneficiaries need Part B; the amount of coverage that's considered adequate; and payment procedures.
- Most believed they have received enough information from employers, mailed pamphlets, hospitals and AARP to choose a supplemental insurer. However, their confusion about components of the Medicare program and coverage levels suggests they would also benefit from additional information about how supplemental insurance is structured and the kinds of coverage it provides.
- African American participants said they want clearer information about the costs of joining HMOs.
- African-American beneficiaries were not interested in information from HCFA to help them select health care providers. They prefer to rely on advice from friends and family, and on their own assessments of providers' interpersonal skills. They might benefit from information about important factors involved in selecting a provider. Interpersonal skills are salient to beneficiaries, so it may be important to remind them about other factors such as experience and training.
- African American beneficiaries want more information about healthcare concerns specific to their race.
- African American beneficiaries want to know more about how Medicare funds are used, how the program is evolving, and what's being done to preserve their benefits under the program.

How can information be most effectively made available to African-American beneficiaries?

- There were broad differences among African-American beneficiaries in terms of their preferred sources of information about the Medicare program and about health in general.
- African-American beneficiaries ranked HCFA high both in terms of how much information they receive and in terms of how much they trust that information.
- African American beneficiaries may welcome more information from AARP, in whom they place a greater amount of trust than they do in other sources.
- African American beneficiaries are already getting a large amount of information from the mass media, but they don't trust the media to provide accurate information.
- African-American beneficiaries who have well-established relationships with their medical providers rely on and trust them as sources of Medicare information.
- African American beneficiaries prefer receiving written material in the mail, in part because printed materials can be used for future reference.
- Privacy protection must be provided before this generation of African-American beneficiaries would be interested in using computers to access information about the Medicare program or other health-related issues.

- African-American beneficiaries reported that automated phone menus are long and complicated. They prefer speaking with a human operator.

6.2 Hispanic Beneficiaries

What information do Hispanic beneficiaries want and need from HCFA?

- Hispanic beneficiaries' needs and preferences differ depending on whether or not they are fluent in English.
- Hispanic beneficiaries are careful consumers who need clearer, more accessible information. Particularly for Spanish-speaking Hispanic beneficiaries, there are gaps in basic knowledge about billing procedures, coverage for health care services, and the role of supplemental insurers.
- Many Spanish-speaking Hispanic beneficiaries rely on English-speaking friends and relatives to obtain and translate information. However, they would prefer increased access to Spanish-language written materials, and to Spanish-speaking telephone operators, case workers, and health care providers.
- Spanish- and English-speaking Hispanic beneficiaries agree that they want more information from HCFA about how to recognize and report fraud. They are also concerned about the future of the Medicare program and would like information about how the program is evolving and how changes are likely to affect them.
- Hispanic beneficiaries may be receptive to help from HCFA in choosing a health care provider since they generally have high confidence in medical professionals and identified providers' interpersonal skills as less important than language and whether or not providers accept Medicare patients.
- English-speaking Hispanics were wary of the financial incentives that characterize HMO plans. They would benefit from accurate information about HMOs, and they seem more likely to trust information from HCFA than information that comes directly from HMOs.
- Spanish- and English-speaking Hispanic beneficiaries already get information about staying healthy from health care providers and the media; but they would like more information on some topics such as diet and exercise, breast cancer, high blood pressure, diabetes, and prostate cancer.

How can information be most effectively made available to Hispanic beneficiaries?

- Mass media, family, friends and community resources are important information sources for Spanish-speaking Hispanic beneficiaries and for Hispanic beneficiaries with low literacy levels.
- English-speaking Hispanic beneficiaries reported receiving and trusting information from supplemental insurance companies.
- Spanish-speaking Hispanics had very little knowledge of or experience with Medicare contractors.
- English-speaking Hispanics reported strong trust in information they receive from their health care providers. Spanish-speaking Hispanics also rely on medical providers for information, but aren't always satisfied with the information they receive.
- Spanish-speaking Hispanic beneficiaries rely heavily Spanish radio and television for information. English-speaking Hispanic beneficiaries also rely on and trust media sources more than other beneficiary subpopulations do.
- Spanish-speaking Hispanics are more likely to rely on community resources for information than any other subgroup.
- Spanish-speaking Hispanics said the Social Security Administration (SSA) is an important information source for them, particularly because the SSA provides access to Spanish-speaking caseworkers.
- Spanish-speaking Hispanic beneficiaries were interested in receiving Spanish-language Medicare Handbooks. Few Spanish-speaking beneficiaries knew whether Spanish-language Handbooks are available or how to get a copy of one.

- Spanish- and English-speaking Hispanic beneficiaries prefer to receive written material through the mail. Spanish-speaking beneficiaries were particularly interested in Spanish-language materials, but printed English-language materials are more useful to them than other forms of English-language information, because English-speaking family and friends can help interpret printed materials.
- Although there was some enthusiasm for computers, Hispanic beneficiaries were skeptical about whether computers would actually improve their access to accurate and timely information.

6.3 Dually Eligible Beneficiaries

What information do dually eligible beneficiaries want and need from HCFA?

- Dually eligible beneficiaries are particularly likely to be passive information-seekers, so it may be important to identify methods for encouraging more active information seeking strategies. It will also be important to identify distribution channels that are likely to deliver information to beneficiaries who are probably not looking for it.
- Dually eligible beneficiaries are confused about many aspects of the programs they use. In addition, they have difficulty articulating the types of information they need.
- Dually eligible seniors need more information about Medicare and Medicaid's components and how the programs work together to provide coverage. They're also confused about how spend-down works.
- Dually eligible beneficiaries have difficulty finding providers who will accept them. They will benefit from information to help them identify providers they can use. They will also benefit from efforts to increase their access to quality health care providers.
- Dually eligible beneficiaries think they receive enough information about HMOs. Many dually eligible focus group participants reported that they have not considered joining an HMO because of inconvenience, long waiting times and reduced access to providers.
- Low literacy levels are an important barrier preventing dually eligible beneficiaries from accessing needed information.

How can information be most effectively made available to dually eligible beneficiaries?

- Dually eligible beneficiaries trust HCFA less than other subgroups do, in part because they are concerned about how changes in the Medicare program may affect their eligibility. In addition, they often portray their relationship with "official" sources such as HCFA as adversarial.
- Dually eligible beneficiaries ranked medical providers highest for amount of and trust in information received. This may be related to their preference to avoid official or bureaucratic information channels.
- Dually eligible beneficiaries are confused about who Medicare contractors are, perhaps because they don't interact with or receive much information from Medicare contractors.
- Dually eligible beneficiaries do not rely on or trust information from the mass media.
- Dually eligible beneficiaries receive more information from and have more trust in community resources relative to other beneficiary subpopulations. Dually eligible beneficiaries rely on family and friends less than other beneficiary subpopulations.
- Although dually eligible beneficiaries are more likely to get information from face-to-face interactions or the mass media, a substantial number rely on written materials.
- Dually eligible beneficiaries were not enthusiastic about using computers and the Internet to access information about Medicare, Medicaid and health-related issues.
- Dually eligible beneficiaries reported frustrations with automated phone menus because there are often too many options that are too long and that are read too quickly. In addition, dually eligible beneficiaries reported that it is often difficult for them to match available menu options to their specific questions and needs. At the same time, dually eligible beneficiaries did not express the

strong preference for speaking with human operators that was common in other beneficiary subpopulations.

6.4 Rural Beneficiaries

What information do rural beneficiaries want and need from HCFA?

- Rural beneficiaries perceive the Medicare program as complicated, and they're confused about the relationship between Medicare and Social Security.
- Rural participants want to see more detailed itemization on the EOMB form, as well as codes that are easier to understand.
- Rural beneficiaries reported that their own lack of experience, late-arriving materials, and difficulty weighing information from several sources are all obstacles to deciding among supplemental insurance companies.
- Seniors who live in rural areas appear to understand Medicare assignment and how to work with providers who don't accept assignment.
- Rural participants were less concerned than general population beneficiaries were about conflicting and changing information on staying healthy.

How can information be most effectively made available to rural beneficiaries?

- Of all the subpopulations, rural beneficiaries ranked HCFA highest for amount of information received.
- Rural beneficiaries don't turn to family and friends for information as much as general population beneficiaries do, in part because they like to keep information about their health private. For the same reason, in addition to lack of access, community resources were not identified as an important information source. These factors may contribute to making HCFA a particularly important resource for rural beneficiaries.
- Rural participants ranked insurance carriers high on both amount of and trust in information they provide. They also ranked medical providers high on both factors. In contrast, rural beneficiaries ranked supplemental insurers low on trust.
- More so than other subgroups, rural beneficiaries stressed their preference for printed and in-person information media. Rural beneficiaries noted that print media have an important advantage because they can be saved for future reference.
- Rural beneficiaries complained about television and radio as information sources. One of the reasons they cited is the relatively superficial information provided in these media. Rural beneficiaries wanted more specific information, like that provided in detailed magazine articles. Again, they valued print media because they can be used for future reference.
- Rural participants are hesitant to use computers because they view them as too impersonal, insecure, and untimely.
- Rural beneficiaries expressed less frustration with toll free telephone assistance than other beneficiary populations. In particular, rural beneficiaries were relatively patient with long telephone waiting times. Rural beneficiaries reported being more interested in getting accurate information than in getting a prompt response.

6.5 64-Year-Olds About to Enroll in Medicare

What information do individuals about to enroll in Medicare want and need from HCFA?

- Those about to enroll in Medicare are somewhat intimidated by the program and its apparent complexities. Their questions range from specific — whether enrollment is automatic, how one's employment status affects enrollment, length of waiting periods, and how Medicare works with

employer-provided insurance — to general questions about assignment, payment, reimbursement, and coverage. Individuals about to enroll in Medicare will benefit from early information that explains how the Medicare is set up, how the program components work together to provide coverage, and the general types of options available to Medicare beneficiaries.

- Individuals about to enroll in Medicare pre-enrollees are perplexed about the purpose of supplemental insurance and how it works.
- Those who are about to enroll also have concerns about Medicare HMOs, including quality of care, restricted provider choice, continuity of care and convenience.
- Another important issue for individuals about to enroll in Medicare is the role Medicare will play in their budgets.

How can information be most effectively made available to individuals about to enroll in Medicare?

- Many individuals about to enroll in Medicare learn about the program from spouses and other family members who are already enrolled in Medicare. Gap analyses of source rankings for individuals about to enroll in Medicare suggest that they may want to receive less information from friends and family and more extensive information from “official” resources like HCFA.
- Individuals about to enroll in Medicare want information in interactive formats such as seminars and group meetings.
- Employers are an important source of information for individuals about to enroll in Medicare, and medical providers are less important compared with other beneficiary subpopulations.
- Individuals about to enroll in Medicare ranked HCFA highly in terms of amount of information and its trustworthiness, perhaps because pre-enrollees have had less contact with supplemental and carrier insurers.
- Although most individuals about to enroll in Medicare have had little direct experience with supplemental insurers, they have been exposed to these companies’ marketing efforts and may have already made decisions about their options under Medicare.
- Since membership in AARP can begin at 55 years old, this organization can be an important source of information about Medicare for people about to enroll in Medicare.
- Those about to enroll in Medicare would benefit from early delivery of Medicare materials including the Medicare Handbook and other enrollment materials.
- While some individuals about to enroll in Medicare appreciated television as an information source, most expressed a preference for written information.
- Several of those about to enroll questioned the motives of companies that distribute videotaped information. They also expressed concern about the timeliness of videotaped information.
- Individuals about to enroll in Medicare are skeptical that current seniors would be interested in using computers for health-related information.
- Individuals about to enroll in Medicare had complaints about 800-numbers that were similar to those of the general population. However, pre-enrollees reacted positively to some concrete scenarios, particularly when the automated services were described as cost-saving measures.

APPENDIX A

Market Research for Medicare Beneficiaries Focus Group Protocols

HCFA On-line: Market Research for Medicare Beneficiaries
Focus Group Protocol
November 25, 1996

- **I. Introduction [5 minutes]**

- Good afternoon (evening) and welcome to our session. My name is _____. I work for Westat, a research firm located just outside of Washington, DC. As you may have been told, the Health Care Financing Administration (HCFA), the Federal agency in charge of Medicare, has hired us to come and speak to folks like yourselves about the information you need about the Medicare program and more generally about the information you need about your health and health care.
- The technique I am using today is called a focus group. We are going to focus our discussions on information about Medicare and information about your health. Before we begin, let me remind you of some ground rules.
- We will be on a first name basis only. *[MAKE SURE ALL NAME CARDS FACE TOWARD YOU AND THAT NONE ARE OBSTRUCTED]*
- There are no right or wrong answers in this room--just your opinions. I need to hear what each of you thinks about the topics we are going to discuss, so please speak up. Feel free to disagree, but please wait your turn to speak. You may refer to each other, but please use only the first names on the name cards. Only one person should talk at time.
- Behind me is a one-way mirror. There is a colleague from Westat [and some representatives from Medicare] who will be watching. They want to learn as much as possible from your opinions. We are also tape recording the session because we don't want to miss any of your comments.
- This is a research project. There will be a report written about what we have learned from you and from other people we are talking with both in this area and in other parts of the country. Some of your words may be part of our report; however, no names will be used in the report, and Medicare won't be given any names or information about you. What you say will have no effect on your Medicare benefits, so please be frank. What you say will help Medicare be more responsive to the information needs of beneficiaries.
- Our session will last about an hour and a half to two hours.

- Are there any questions before we begin? Just a few logistics. The restroom facilities are located _____. There are no scheduled breaks since we have so much to discuss. However, please feel free to excuse yourself if necessary.
- I've passed out an Information Sheet. Let's take a minute or two and fill out the front of that sheet. We'll get to the back in just a few minutes.
- Let's start our discussion by going around the table. Introduce yourself and tell us what got you interested in this discussion about health and health care. I'll start.

- **II. Information about the Medicare program**
- **A. Who is “Medicare”? [10 minutes maximum]**
- You’re all here because you are enrolled in Medicare, which is a health insurance plan for people over 65 and for some people under 65 who are disabled. Almost everybody in the United States over 65 is on Medicare. My first question for you is, Who do you think of when I say “Medicare”?
- *Probe if needed:* Is it a government agency or an insurance company or what?
- *Encourage some discussion, but limit this section.*
- *If no one mentions HCFA, probe:* Do you know who runs the Medicare program?
- *If no one mentions HCFA still:* Have you heard of the Health Care Financing Administration?
- *If no one knows who HCFA is, say:* The Health Care Financing Administration is the Federal government agency that manages the Medicare program. They are part of the Department of Health and Human Services. Do you remember seeing the name on any letters or pamphlets from Medicare or on the Medicare Handbook?
- **B. Recent experiences getting information about Medicare [20 minutes]**
- I’d like you to think about a time recently that you tried to get information about the Medicare program -- any kind of information at all. What information have you tried to get recently?
- *OPTIONAL: On a flip chart or white board with two columns, write the information items desired as they are reported. As an information item is reported, ask if others have tried to get the same information.*
- *After all information items recorded:* From whom did you try to get this information?
- *Record sources on flip chart, match up with information items. As a source is mentioned, ask if others have tried to get information from that source.*
- *After getting sources, follow up on each source/item reported (or as many as time allows).*
- What form was the information in? (i.e., booklet, letter, Q&A, audio, video, on-line) Did you understand the information? Was it accurate and complete? Was it what you needed?

- *If anyone mentions “Medicare” as a source of information, probe:*
 - Who do you mean when you say “Medicare” -- what was the name of the organization you called? [Did you call the government agency that manages the program, an insurance company that pays the claims, or whom?]
- C. Card sort -- where received information about Medicare [20 minutes]**
- Next, I’d like you to think about all of the sources from which you have received information about the Medicare program. On the table in front of you are several sets of cards. I’d like you to take stack number 1 now. Each of the cards in Stack 1 has one possible source of Medicare information. Let me read the sources:
 - A. your family or friends;
 - B. the insurance companies that pay claims for Medicare;
 - C. your doctors, nurses, or clinics;
 - D. radio, television, and newspapers;
 - E. the Health Care Financing Administration (the Federal government agency that manages Medicare);
 - F. your supplemental insurance company; [Medicaid/your HMO]
 - G. people in your community, such as at senior centers, churches, libraries, etc.;
 - H. organizations such as AARP and magazines for senior citizens. [not for disabled group]
 - What I’d like you to do is to sort the cards in order by how much information about Medicare you have received from each source. That is, you would put the card for the source from which you have received the most information on top, the one for the next most information under that, and so on, with the source from which you have received the least information on the bottom.
 - Are there any questions?
 - *When everyone has finished, ask them to record in Column II of the Information Sheet the letter of each card next to the number of its order in the stack -- the top card is number 1, etc.*
 - What did you have as the top card? *Encourage discussion of choices for top one or two information sources.*

- *Throughout this exercise, as participants mention Medicare carriers, HCFA, or supplemental insurers, probe to determine whether they are clear on which one they are talking about*
- *After discussion of sources providing the most information:* Are these sources you've selected at the top of your list particularly convenient or inconvenient ways for you to get information?
- And which card did you have on the bottom? *Encourage discussion of choices for bottom one or two information sources.*
- *After discussion of sources providing the least information:* Are these sources you've selected at the bottom of your list particularly convenient or inconvenient ways for you to get information?
- Are there any information sources that you use that we didn't list on one of the cards? Are there any sources you would *like* to use or to use more?

<ul style="list-style-type: none"> • <i>If more than 45 minutes into session, skip the next card sort.</i>

- Next, I'd like you to sort the same cards again -- this time, by how much you trust the source to give you accurate, complete, and understandable information about Medicare. The top card would be the source you trust the most for information about Medicare, the bottom the source you trust the least.
- *Ask participants to record this card order in Column III on the Information Sheet*
- Now which card was on top? *Encourage discussion of most accurate and understandable sources. Probe as needed:* Why do you trust {SOURCE] to for information about Medicare?
- And which card was on the bottom? *Encourage discussion of least accurate and understandable sources. Probe as needed:* Why don't you trust {SOURCE] to be accurate and understandable?
- **D. Medicare Handbook [5 minutes]**
- *Hold up copy of Medicare Handbook.*
- Do you recognize this? How many do? _____
- Do you have one at home? How many do? _____
- Do you ever use it? How many do? _____
- What kind of information do you look up in it?

- *If more than one hour has passed, skip the following:*
- Is it clear? Does it have information you need? What's missing or not clear? *Encourage discussion of specific uses, if any mentioned.*
- **E. Information about Medicare Still Needed [10 minutes]**
- We've talked a lot about the information you *get* about the Medicare program. What about information you *don't* get? Is there information you need but don't get about the Medicare program? *Probe for details of information needs, why information is needed.*
- What about information you get but don't understand? Is there anything about the Medicare program that you don't understand and would like clearer information about? *Probe for details of needs, why information needed.*
- Where or how would you like to get this information? *Follow up with each need mentioned.*

- **III. Information about Supplemental Insurance [10 minutes]**
- People enrolled in Medicare often have other health insurance as well. Some people have what are called supplemental or “Medigap” policies that pay the deductibles, copayments, and for some services Medicare doesn’t cover. Other people have supplemental insurance that covers just long term care, things like stays in a nursing home. Still other people have supplementary coverage through the Medicaid program.
- How many of you have supplementary health insurance that pays for some of the things Medicare doesn’t cover?
- How many of you had a *choice* of different plans for your supplementary coverage?
- Do you feel as though you had enough information about supplementary insurance to make the choice? What other information would you like to have to make this kind of a choice? How would you like to get this information? (In what form and from whom?)

- **IV. General Health Information Needs**

- I'd like to change the subject a little at this point. We've been talking about the information you need about the Medicare program and other health insurance and how you get that information. The agency that runs Medicare would like your advice about other health-related information you need and how they might help you get that information. There are many different areas that might be included here -- I'd like to take a few of them one at a time.

- **A. Information about Choosing a Doctor [10 minutes]**

- First, how about choosing a doctor?
- Do you feel like you get the information you need to help you choose a primary care or "regular" doctor?
- *If "Yes":* What information do you get? From whom? How is it presented? Do you trust it?
- *If "No":* What information would you like to have? How would you like to get that information?
- Do you feel like you get the information you need to help you choose a specialist?
- *If "Yes":* What information do you get? From whom? How is it presented? Do you trust it?
- *If "No":* What information would you like to have? How would you like to get that information?

- **B. Information about Staying Healthy [10 minutes]**

- Next, what about information about ways to stay healthy, such as what foods you should eat and what kind of exercise you should get.
- Do you feel like you get the information you need to help stay healthy?
- *If "Yes":* What information do you get? From whom? How is it presented? Do you trust the information?
- *If "No":* What information would you like to have? How would you like to get the information?
- *P If preventive services not mentioned:* Do you feel like you get the information you need about preventive medical care, like check-ups, mammography, and flu shots?

- *If “Yes”*: What information do you get? From whom? How is it presented? Do you trust the information?
- *If “No”*: What information would you like to have? How would you like to get the information?
- **D. Other Information Needs [5 minutes]**
- We’ve talked about getting information about the Medicare program, about choosing a doctor, and about information on staying healthy. These are only some areas dealing with your health and health care in which you might need information. We don’t have time to talk in detail about other areas, but I’d like to give you a chance to mention any that you think are important. Remember, we’re asking for your advice to the Medicare program about the information you need about health and health care.
- In what other areas do you feel that you need information? *Continue to elicit suggestions, probing for clarity, but do not get into extended discussion about any particular area.*
- **E. Sources of Information [15 minutes]**
- We’ve talked about many different sources of information about your health. I’d like to ask you briefly about a series of sources, and get an idea of what you think is good about the information you get from that source, and what is bad about it. For example, you might like the way information is presented, you might trust one source over another, you might find the some information more suited to your own needs, you might find some information too hard to understand.
- *For each source that has not been thoroughly discussed previously, probe:* What’s good about the information you get from [SOURCE]? What’s not so good about it?
- *Sources:*
 - your family and friends
 - your doctors or nurses
 - your health insurance plan
 - newspapers, radio, and television
 - AARP or other senior citizens’ groups
 - your local library
 - senior centers or other community sources

- the Medicare program
 - the Surgeon General
 - *other sources mentioned in the discussion*
- **F. Information Media [15 minutes]**
- Finally, I'd like to talk a bit about the different media through which you get information about your health and health care. By "media," I mean written material, TV or video, telephone conversations, face-to-face conversations, and so on. Again, I'd like you to say a bit about what's good and what's not so good about each medium, or way of getting information.
- *For each medium, probe: What's good about getting health information this way? What's not so good about it? Try to focus discussion on medium, rather than source or content.*
- *Media:*
 - radio and television
 - videos [Has anyone obtained health information from videos, either at home or at a library or community center? What kind of information was it?]
 - newspapers and magazines
 - notices you get in the mail
- **800 numbers/automated phone menus**
- What about 800 numbers? How many of you have tried to get information about Medicare or some other health topic by calling an 800 number?
- And how many of you have reached a recorded message asking if you have a touch tone phone when you called an 800 number?
- What do you do when you reach that kind of message, where you might have to enter some numbers to get to where you want to go?
- *If people express anger or frustration about automated phone menus, probe for the reason for the anger/frustration.*
- Suppose you didn't have to do anything other than wait for someone to come on the line. How is that, compared with having to enter numbers?
- How long would you be willing to wait on such a call before you got impatient -- 10 seconds, 30 seconds, a minute, three minutes, five minutes?

- When you have to enter a number from a list the machine reads to you, does the length of the list make a difference to you? How many options do you think is too many (two, three, four, five . . .)?
- How about when you enter one number, and then get to another menu that asks you to enter another number? Is that a problem? How many selections are you willing to make to get what you want (one, two, three, four, five . . .)?
- **Computers/Internet**
- One more way to get health information is by using a computer.
- How many of you use computers?
- Do any of you use the Internet? Do you get health information from the Internet?
- HCFA is thinking about helping you get access to computers in public places such as libraries, senior centers, and Medicare offices.
- What would you think about getting (INSERT INFORMATION TYPE) through these computers? Do you think there are any drawbacks to getting this kind of information by computer?
 - (information about how Medicare works)
 - information about supplemental insurance plans
 - (information about managed care plans)
 - general instructions on how to file Medicare claims
 - general information about what's covered and what Medicare pays
 - information about your own personal claims

What would you want to be able to find out about your claims? (Would you want to get basic information about who has filed claims for your care, when the claim was filed, and whether it was paid? Would you want descriptions of services received? Would you want information about the codes and identification numbers on the claim forms?)

Do you think a computer is a good way to get this kind of information? What makes you say that? Do you think there are drawbacks to getting this kind of information by computer? (Do you think people would feel comfortable using a computer to get access to their personal Medicare records?)

- **Summary on Sources**
- Now that we've talked about all these different ways of getting information about Medicare and other health-related topics, where would you most like to be able to get health information?

- **IV. Wrap-up [2 minutes]**
- Thank you very much for your time. This has been very helpful.
- *Describe procedures for getting paid, how to leave, any other logistical details.*
- We have put out some information that you might find helpful. *Say where it is.* Feel free to take one of any of the materials you want. Please don't take more than one, though, because we only brought a limited supply.
- Again, thanks for your help.
- *Table has Medicare Handbook, other HCFA pubs; 15 copies each. Count and record how many are taken of each pub.*

• Focus Group Information Sheet

- | | |
|---|---|
| <ul style="list-style-type: none"> • • 1. Are you male or female? • <input type="checkbox"/> Male • <input type="checkbox"/> Female • 2. How old are you? • <input type="checkbox"/> under 65 • <input type="checkbox"/> 65-69 • <input type="checkbox"/> 70-74 • <input type="checkbox"/> 75-79 • <input type="checkbox"/> 80-84 • <input type="checkbox"/> 85 or older • 3. Do you take care of your own paperwork for Medicare, or does someone else, like your husband or wife or a child, do it for you? • <input type="checkbox"/> Do it myself • <input type="checkbox"/> Someone else does it • 4. Are you of Hispanic origin (e.g., Cuban, Mexican, Puerto Rican, Latino)? • <input type="checkbox"/> Yes • <input type="checkbox"/> No | <ul style="list-style-type: none"> • • 5. What is your race? • <input type="checkbox"/> White • <input type="checkbox"/> Black or African-American • <input type="checkbox"/> Asian or Pacific Islander • <input type="checkbox"/> American Indian or Alaska Native • <input type="checkbox"/> Other • 6. How far did you get in school? • <input type="checkbox"/> 6th grade or less • <input type="checkbox"/> 7th grade through 12th grade • <input type="checkbox"/> High school graduate • <input type="checkbox"/> Some college • <input type="checkbox"/> College graduate • <input type="checkbox"/> Graduate degree • 7. Have you ever been in a focus group before? • <input type="checkbox"/> Yes • <input type="checkbox"/> No • |
|---|---|

HCFA On-line: Market Research for Medicare Beneficiaries
Draft Focus Group Protocol
PRE-ENROLLEES
November 29, 1996

- **I. Introduction [5 minutes]**

- Good afternoon (evening) and welcome to our session. My name is _____. I work for Westat, a research firm located just outside of Washington, DC. As you may have been told, the Health Care Financing Administration (HCFA), the Federal agency in charge of Medicare, has hired us to come and speak to folks like yourselves about the information you need about the Medicare program and more generally about the information you need about your health and health care.
- The technique I am using today is called a focus group. We are going to focus our discussions on information about Medicare and information about your health. Before we begin, let me remind you of some ground rules.
- We will be on a first name basis only. I am going to pass out cards to you. Please write down your first name on both sides of the card and place the card in front of you on the table. *[MAKE SURE ALL CARDS FACE TOWARD YOU AND THAT NONE ARE OBSTRUCTED]*
- There are no right or wrong answers in this room--just your opinions. I need to hear what each of you thinks about the topics we are going to discuss, so please speak up. Feel free to disagree, but please wait your turn to speak. You may refer to each other, but please use only the first names on the name cards. Only one person should talk at time.
- Behind me is a one-way mirror. There is a colleague from Westat [and some representatives from Medicare] who will be watching. They want to learn as much as possible from your opinions. We are also tape recording the session because we don't want to miss any of your comments.

- This is a research project. There will be a report written about what we have learned from you and from other people we are talking with both in this area and in other parts of the country. Some of your words may be part of our report; however, no names will be used in the report, and Medicare won't be given any names or information about you. What you say will have no effect on your Medicare benefits, so please be frank. What you say will help Medicare be more responsive to the information needs of beneficiaries.
- Our session will last about an hour and a half to two hours.
- Are there any questions before we begin? Just a few logistics. The restroom facilities are located _____. There are no scheduled breaks since we have so much to discuss. However, please feel free to excuse yourself if necessary.
-
- I've passed out an Information Sheet. Let's take a minute or two and fill out the front of that sheet. We'll get to the back in just a few minutes.
-
- **B. Introduction (5 minutes)**
- You're all here because you are about to enroll in Medicare, which is a health insurance plan for people over 65 and for some people under 65 who are disabled. Almost everybody in the United States over 65 is on Medicare.
- Let's start our discussion by going around the table. Introduce yourself and tell us where you are in the process of enrolling for Medicare? (What have you done so far? Have you heard from the government yet? What's will you be facing next?)

- **II. Information about the Medicare program**
- **A. Who is “Medicare”? [10 minutes maximum]**
- My next question for your is, Who do you think of when I say “Medicare”?
- *Probe if needed:* Is it a government agency or an insurance company or what?
- *Encourage some discussion, but limit this section.*
- *If no one mentions HCFA, probe:* Do you know who runs the Medicare program?
- *If no one mentions HCFA still:* Have you heard of the Health Care Financing Administration?
- *If no one knows who HCFA is, say:* The Health Care Financing Administration is the Federal government agency that manages the Medicare program. They are part of the Department of Health and Human Services. Do you remember seeing the name on any letters or pamphlets from Medicare?

- **B. Recent experiences getting information about Medicare [20 minutes]**

- Now I'd like to find out whether you've received any information yet about the Medicare program -- any kind of information at all. Have you received any information yet? What information have you received? Where did that information come from?
- 1. Have you tried to get any information about Medicare for yourself? What did you want to know? Who did you contact for information?
- *Follow up on each source/item reported (or as many as time allows).* What kind of information did you get? Did you understand the information? Was it accurate and complete? Was it what you needed?
- 2. Have you tried to help someone else get information about Medicare (such as a family member or friend)? Who did you help? What did they want to know? (e.g., claims; coverage). Who did you contact for information?
- *Follow up on each source/item reported (or as many as time allows).* What kind of information did you get? Did you understand the information? Was it accurate and complete? Was it what you needed?

- | |
|---|
| <ul style="list-style-type: none">• <i>If anyone mentions "Medicare" as a source of information, probe:</i>• Who do you mean when you say "Medicare" -- what was the name of the organization you called? [Did you call the government agency that manages the program, an insurance company that pays the claims, or whom?] |
|---|

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- **C. Card sort -- where received information about Medicare [20 minutes total]**
- Next, I'd like you to think about all of the sources from which you have received information about the Medicare program. On the table in front of you is a set of cards. Each of the cards in the stack has one possible source of Medicare information. Let me read the sources:
 - A. your family or friends;
 - B. the insurance companies that pay claims for Medicare [the carrier who contracts with Medicare to pay the bills];
 - C. your doctors, nurses, or clinics;
 - D. radio, television, and newspapers;
 - E. the Health Care Financing Administration (the Federal government agency that manages Medicare);
 - F. your supplemental insurance company; [which may be an insurance company, Medicaid or an HMO]
 - G. people in your community, such as at senior centers, churches, libraries, etc.;
 - H. organizations such as AARP and magazines for senior citizens. [not for disabled group]
- Sort the cards in order by how much information about Medicare you have received from each source. So, put the card for the source from which you have received the most information on top, the one for the next most information under that, and so on, with the source from which you have received the least information on the bottom.
- Are there any questions?
- *(Participants who have received no information yet may choose to group all sources together in last place.) When everyone has finished, ask them to record their sorting in the first column on the back of the Information Sheet. They should record the letter of each card next to the number of its order in the stack -- the top card is number 1, etc.*
- What did you have as the top card? *Encourage discussion of choices for top one or two information sources.*

- What did you have as the bottom card? *Encourage discussion of last information source.*
- Next, I'd like you to sort the same cards again -- this time, by how much you trust the source to give you accurate, complete, and understandable information about Medicare. The top card would be the source you trust the most for information about Medicare, the bottom the source you trust the least.
- *Ask participants to record this card order in the second column on the back of the Information Sheet*
- Now which card was on top? *Encourage discussion of most accurate and understandable sources. Probe as needed: Why do you trust {SOURCE} to for information about Medicare?*
- And which card was on the bottom? *Encourage discussion of least accurate and understandable sources. Probe as needed: Why don't you trust {SOURCE} to be accurate and understandable?*

- **D. Medicare Handbook [5 minutes]**

- *Hold up copy of Medicare Handbook.*
- Do you recognize this? How many do? _____
- Do you have one at home? How many do? _____
- *If anyone has received the booklet, ask:* Have you read it or looked it over? How many have? _____
- What would you think about receiving a booklet like this when you enroll for Medicare? Do you think that would be helpful or not? What would be good about that? Do you think there might be drawbacks to that?

- **E. Information about Medicare for New Enrollees [10 minutes]**

- Now, let's talk about the kinds of information you want to receive when you enroll in Medicare.
- In general which approach would be better for you? (1) Getting a lot of information in the mail right away when you enroll for Medicare OR (2) Receiving some basic information right away, including someone to contact when you want more information?
- (What do you think of these two approaches? What are the good things about them? What are the drawbacks?)
- What kinds of information do you think are important to have right away, when you first enroll in Medicare? (*Probe for why that's important.*)

- **F. Early Contacts from Managed Care and Other Insurance Companies [10 minutes]**

- Sometimes people received brochures or phone calls from managed care companies or HMOs advertising their health plans. How many of you have received printed materials or phone calls like this?
- Tell me about that information. What do you think about it? Was it helpful? Confusing? Tell me about that.
- Would you like Medicare to send you information about these plans when you first enroll? What kind of information would be helpful?

- **G. Other Information about Medicare [5 minutes]**

- We've talked about Medicare information you have received or would like to receive when you enroll for Medicare. Are there any other kinds of information you think you need about the Medicare program that we haven't talked about yet?
- *Probe for details of information needs, why information is needed.*
- When would you like to get this information? How would you like to get this information? *Follow up with each need mentioned.*

- **III. Information about Supplemental Insurance [10 minutes]**
- People enrolled in Medicare often have other health insurance as well. Some people have what are called supplemental or “Medigap” policies that pay the deductibles, copayments, and for some services Medicare doesn’t cover. Other people have supplemental insurance that covers just long term care, things like stays in a nursing home. Still other people have supplementary coverage through the Medicaid program.
- How many of you have heard about supplementary health insurance that pays for some of the things Medicare doesn’t cover?
- Have you been thinking about supplementary insurance? What kinds of things have you been thinking?
- Have you been receiving information about supplementary insurance? What information have you received? From whom? Tell me about that.
- What information do you think you need about supplemental insurance? Who would you like to receive that information from? When would that information be useful? (Right now? When you enroll? After you enroll?)

- **IV. General Health Information Needs**

- I'd like to change the subject a little at this point. We've been talking about the information you need about the Medicare program and other health insurance and how you get that information. The agency that runs Medicare would like your advice about other health-related information you need and how they might help you get that information. There are many different areas that might be included here -- I'd like to take a few of them one at a time.

- **A. Information about Choosing a Doctor [10 minutes]**

- First, how about choosing a doctor?
- Do you feel like you get the information you need to help you choose a primary care or "regular" doctor?
- *If "Yes":* What information do you get? From whom? How is it presented? Do you trust it?
- *If "No":* What information would you like to have? How would you like to get that information?
- Do you feel like you get the information you need to help you choose a specialist?
- *If "Yes":* What information do you get? From whom? How is it presented? Do you trust it?
- *If "No":* What information would you like to have? How would you like to get that information?

- **B. Information about Staying Healthy [10 minutes]**

- Next, what about information about ways to stay healthy, such as what foods you should eat and what kind of exercise you should get.
- Do you feel like you get the information you need to help stay healthy?
- *If "Yes":* What information do you get? From whom? How is it presented? Do you trust the information?
- *If "No":* What information would you like to have? How would you like to get the information?

- *P If preventive services not mentioned:* Do you feel like you get the information you need about preventive medical care, like check-ups, mammography, and flu shots?
- *If “Yes”:* What information do you get? From whom? How is it presented? Do you trust the information?
- *If “No”:* What information would you like to have? How would you like to get the information?
- **D. Other Information Needs [5 minutes]**
- We’ve talked about getting information about the Medicare program, about choosing a doctor, about information on staying healthy, and learning chronic conditions. These are only some areas dealing with your health and health care in which you might need information. We don’t have time to talk in detail about other areas, but I’d like to give you a chance to mention any that you think are important. Remember, we’re asking for your advice to the Medicare program about the information you need about health and health care.
- In what other areas do you feel that you need information? *Continue to elicit suggestions, probing for clarity, but do not get into extended discussion about any particular area.*
- **E. Sources of Information [Use these probes as necessary to gather information not discussed with card sort tasks.]**
- We’ve talked about many different sources of information about your health. I’d like to ask you briefly about a series of sources, and get an idea of what you think is good about the information you get from that source, and what is bad about it. For example, you might like the way information is presented, you might trust one source over another, you might find the some information more suited to your own needs, you might find some information too hard to understand.
- *For each source, probe:* What’s good about the information you get from [SOURCE]? What’s not so good about it?
- *Sources:*
 - your family and friends
 - your doctors or nurses
 - your health insurance plan

- newspapers, radio, and television
 - AARP or other senior citizens' groups
 - your local library
 - senior centers or other community sources
 - the Medicare program
 - the Surgeon General
 - *other sources mentioned in the discussion*
- **F. Information Media [15 minutes total]**
 - Finally, I'd like to talk a bit about the different media through which you get information about your health and health care. By "media," I mean written material, TV or video, telephone conversations, face-to-face conversations, and so on. Again, I'd like you to say a bit about what's good and what's not so good about each medium, or way of getting information.
 - *For each medium, probe: What's good about getting health information this way? What's not so good about it? Try to focus discussion on medium, rather than source or content.*
 - *Media:*
 - radio and television
 - videos [Has anyone obtained health information from videos either at home or at a library or community center? What kind of information was it?]
 - newspapers and magazines
 - notices you get in the mail
 - **1. 800 Numbers/Automated Phone Menus**
 - What about 800 numbers? How many of you have tried to get information about Medicare or some other health topic by calling an 800 number?
 - And how many of you have reached a recorded message asking if you have a touch tone phone when you called an 800 number?
 - What do you do when you reach that kind of message, where you might have to enter some numbers to get to where you want to go?

- *If people express anger or frustration about automated phone menus, probe for the reason for the anger/frustration.*
- Suppose you didn't have to do anything other than wait for someone to come on the line? How is that, compared with having to enter numbers?
- How long would you be willing to wait before you got impatient? 10 seconds, 30 seconds, a minute, 3 minutes, 5 minutes?
- When you have to enter a number from a list the machine reads to you, does the length of the list make a difference to you? How many options do you think is too many? (Two, three four, five...)
- How about when you enter one number and then get to another menu that asks you to enter another number? Do you think that is a problem? How many layers are you willing to work through to get what you want (one, two, three, four, five...)?
- **2. Computers and the Internet**
- One more way to get health information is by using a computer.
How many of you use computers?
- Do any of you use the Internet? Do you get health information from the Internet?
- HCFA is thinking about helping you get access to computers in public places such as libraries, senior centers, and Medicare offices.
- What would you think about getting (INSERT INFORMATION TYPE) through these computers? Do you think there are any drawbacks to getting this kind of information by computer?
 - (information about how Medicare works)
 - information about supplemental insurance plans
 - (information about managed care plans)
 - general instructions on how to file Medicare claims
 - general information about what's covered and what Medicare pays
 - information about your own personal claims

- What would you want to be able to find out about your claims? (Basic information about who has filed claims for your care, when the claim was filed, and whether it was paid? Descriptions of services received? Information about the codes and identification numbers on the claim forms?)
- Do you think a computer is a good way to get this kind of information?
- Do you think there are drawbacks to getting this kind of information by computer?
- **IV. Wrap-up [2 minutes]**
- Thank you very much for your time. This has been very helpful.
- *Describe procedures for getting paid, how to leave, any other logistical details.*
- We have put out some information that you might find helpful. *Say where it is.* Feel free to take one of any of the materials you want. Please don't take more than one, though, because we only brought a limited supply.
- Again, thanks for your help.
- *Table has Medicare Handbook, other HCFA pubs, Healthwise for Life; 15 copies each. Count and record how many are taken of each publication.*

APPENDIX B

Market Research for Medicare Beneficiaries Focus Group Recruiting Screener

In order to find out if you are eligible to participate in this study, we need to get some background information.

1. How old are you?

:__:__:

[IF UNDER 64, GO TO SKIP]

[IF EXACTLY 64, RECRUIT FOR “**ABOUT TO ENROLL**” & CONTINUE TO Q6]

[IF 65 OR OLDER GO TO 2]

SKIP: [IF UNDER 64, ASK IF THERE IS SOMEONE ELSE IN THE HOUSEHOLD WHO IS 65 OR OVER THAT YOU COULD SPEAK WITH. IF NOT, THANK AND TERMINATE.]

2. Are you presently receiving benefits from Medicare?

YES :__:

NO :__: [THANK AND TERMINATE INTERVIEW.]

3. Are you enrolled in a Health Maintenance Organization (HMO) through Medicare?

YES :__: [THANK AND TERMINATE INTERVIEW.]

NO :__:

4. Do you regularly receive medical care through the Veterans Administration (VA)?

YES :__: [THANK AND TERMINATE INTERVIEW.]

NO :__:

5. Are you covered by Medicaid or (STATE NAME FOR MEDICAID)?

YES :__: [GO TO Q5a]

NO :__: [GO TO Q6]

- 5a. So you receive both Medicare and Medicaid benefits?

YES :__: [RECRUIT FOR “**DUAL ELIGIBLE**” & CONTINUE WITH Q6]

NO :__: [CONTINUE SCREENER WITH Q6]

6. [IF NOT OBVIOUS, ASK]
Are you male or female?

MALE :__:
FEMALE :__:

7. Do you consider yourself to be...

White, :__:
Black, :__: [RECRUIT FOR “**AFRICAN AMERICAN**” SESSION
BUT CONTINUE TO Q8]
Hispanic, or :__: [RECRUIT FOR “**HISPANIC**” SESSIONS
BUT CONTINUE TO Q8]
some other race/ethnicity? :__:
SPECIFY _____

8. What is the highest grade in school that you have completed?

Less than high school diploma; :__: [RECRUIT FOR “**LOW EDUCATION**” SESSION]
[THIS GROUP WILL BE RACIALLY
& GENDER MIXED]
High school graduate; :__:
Some college; :__:
College graduate; or :__:
Advanced degree. :__:

[ANYONE REMAINING CAN BE RECRUITED FOR “**GENERAL POPULATION**” GROUPS]

[NOTE: “**RURAL**” WAS DETERMINED NOT BY SCREENING, BUT BY ZIPCODE]

[NOTE: FOR “**SPANISH-SPEAKING HISPANIC**” GROUPS, THE DISTINCTION BETWEEN
“**SPANISH**” & “**ENGLISH**” SPEAKING HISPANICS WAS DETERMINED BY BILINGUAL,
FOCUS GROUP FACILITY RECRUITERS]

